



Traumatic brain injury (TBI) 10–20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning

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The goal of this study was to measure the very long-term mental and psychosocial outcomes of severe traumatic brain injury (TBI). Seventy-six persons with severe TBI were evaluated extensively by means of standardized scales, neuropsychological tests and evaluations by family members, at an average of 14.1 (SD = 5.5) years post-injury. Six mental and functional domains were examined: psychiatric symptomatology, cognitive abilities, vocational status, family integration, social functioning, and independence in daily routines. The findings indicate a long-term differential effect of severe TBI, with seriously affected psychiatric symptomatology, family and social domains, as compared to moderately influenced cognitive, vocational and independent functioning. Relatively high rates of depression, psychomotor slowness, loneliness and family members' sense of burden were found. In addition to their epidemiological importance, the results indicate that persons with TBI and their families may need professional assistance to maintain a reasonable psychosocial quality of life, even more than a decade post-injury.

Introduction

The yearly incidence of TBI in industrialized countries is estimated to be 1/2000, with the highest frequency occurring between ages 15–25 [1]. A recent National Institutes of Health (NIH) consensus development panel on rehabilitation of persons with TBI stated that: 'In the US, an estimated 1.5 million to 2 million people incur TBI each year, principally as a result of vehicular incidents, falls, acts of violence, and sports injuries. Approximately 70 000–90 000 individuals incur TBI resulting in long-term, substantial loss of physical and mental functioning' [2]. Systematic measurement of these detrimental consequences has been the subject of many studies over the last three decades. Most of the early studies referred to the acute and post-acute stages of recovery, 1–2 years post-injury, indicating a significant effect of the severity of the injury on outcome [3–6]. Later studies of the long-term consequences of TBI, 5–10 years post-injury, indicated a differential

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course of outcome for different functional domains of life (e.g. [7–9]). Nevertheless, studies examining the very long-term sequelae of TBI, 10–20 years post-injury, are limited in number and in the scope of functional areas examined. Given that the average life expectancy of persons with severe TBI is 50 years post-injury [10], such studies are important both from the epidemiological as well as from the rehabilitative and clinical points of view.

Sbordone *et al.* [11] examined the status of 20 severe TBI patients at an average of 10.3 years post-injury. Their study reports a significant improvement in the subject's cognitive, vocational, motor, behavioural, social and interpersonal functioning during a time span of between 2 years and an average of 10.3 years post-injury, as judged retrospectively by a significant other. These relative's ratings indicated mild-to-moderate difficulties in each of these domains at the very late post-injury phase.

Thomsen [12, 13], on the other hand, reports a less positive outcome of a group of 31 patients with very severe TBI who were interviewed 10–15 years post-injury and then again more than 20 years post-injury. Relatives' ratings and participants' self-ratings were used to assess physical and mental status, behaviour, and personality. At the 20-year follow-up, about half of the participants lived alone; only four were married. A third had severe locomotor difficulties. Impaired memory was reported in all but two of the participants, and most reported some language impairment ranging from word-finding difficulties and dysarthria to complete absence of speech. Aggressive behaviour, violence and sexual disinhibition were reported in 10 of the patients, and six had post-traumatic psychosis. Social contact was minimal, with 19 of the patients having no friends or acquaintances. Only seven (23%) patients were reported to have overall good or rather good psychosocial outcome. In a detailed literature review, Morton and Wehman [14] also emphasize the long-term emotional and social sequelae of TBI. Family members of persons with TBI indicated the change in personality as their primary source of concern, whereas their injured relatives indicated the lack of social contacts as their main source of concern. Oddy *et al.* [9] suggested a cause and effect relationship between personality changes and social withdrawal.

Asikainen *et al.* [15] report a large-scale follow-up of 508 Finnish persons with TBI, 5 years or more post-injury. They present data on the Glasgow Outcome Scale (GOS) and employment status of four age groups and three levels of severity of the injury. In order to compare their findings to these, data on the adult age group with moderate-to-severe injury (ages 17–40 with Glasgow Coma Scale 3–12) was extracted from their report. Of these 140 patients, 57% reported independent employment, 8% were working in subsidized positions, and 35% were unable to work. However, the category 'independent employment' was also assigned to patients who were judged to be capable of working, even though they were unemployed at the time of follow-up. Hence, the actual percentage of employed participants might be lower. In terms of the GOS, 17% fell under the category of 'good recovery', 49% suffered 'moderate disability' and 34% suffered 'severe disability'.

Most studies of long-term outcome of TBI, including this one, are based on uncontrolled clinical samples, i.e. patients admitted to hospitals or rehabilitation centres. Dawson and Chipman [16], who examined a community-based representative sample of persons with TBI at an average of 13 years post-injury, adopted a somewhat different approach. Data on three functional domains—physical

independence, work and social integration—was collected from the Canadian Health and Activity Survey. Only 15% of the participants reported a need for assistance in basic activities of daily living. However, only 25% of the respondents were employed, about a third of them in unpaid jobs. A large degree of social isolation was also reported, with 27% of the sample never socializing at home, and 19% never visiting friends or relatives.

As is evident from this review, the accumulated data fails to present a clear picture of the very long-term functional sequelae of TBI. In general, the studies point, at best, to a medium level of functional disabilities, with an unemployment rate of at least 40–50% and about a 50–60% rate of relative social isolation. The aim of the current study is to enrich and broaden this data by three means. First, by encompassing a broad range of six major domains: psychiatric symptomatology, cognitive abilities, vocational status, family, and social functioning, and independence in Activities of Daily Living (ADL); secondly, by relying on objective and standardized measurements, or significant others' ratings whenever possible, rather than subjective reports; and thirdly, by applying multiple measures for each domain studied, via an extensive evaluation battery. By so doing, this study also follows two recommendations for research set by the NIH consensus panel [2]: 'The duration, natural history and life-course manifestations (neurological, cognitive, social, psychological, economic, etc.) of mild, moderate, and severe TBI should be studied'; and, 'The long-term consequences of TBI of varying severity, including the consequences of ageing for a person with TBI, should be studied'.

Methods

Participants

The present study reports the long-term outcome ($M = 14.1$ years post-injury, $SD = 5.5$) of 76 individuals (63 males) with severe TBI (mean length of coma = 14 days, 63% of the participants having been comatose for more than 1 week and 29% for more than 1 month). This group was drawn from a larger group of 99 participants who were evaluated extensively in a long-term outcome study [17]. The original group of 99 participants was drawn from a list of 321 individuals referred to the 'National Institute for the Rehabilitation of the Brain-Injured' in Israel during a period of 16 years prior to the study. The institute is a public, community-based, neuropsychological rehabilitation centre. The Rehabilitation Department at the Ministry of Defence and the National Insurance Institute refer persons with TBI or other disorders of the central nervous system to the institute for assessment and rehabilitation soon after discharge from physical rehabilitation departments. Referrals include various levels of functional and mental disabilities, excluding severe psychiatric problems or substance abuse. One hundred and ninety-eight (62%) of the 321 referrals suffered from acquired brain injuries of any aetiology. Ninety-nine of them (50%) were not located, or failed to complete the outcome testing. Of the remaining group of 99 persons, only the 76 participants with medically documented TBI whose injury occurred at least 5 years before the current study were included in the present analysis.

Sixty (79%) individuals participated in post-acute neuropsychological rehabilitation programmes after their discharge from physical rehabilitation. Out of the remaining 16 participants, eight reported to have participated in vocational

Table 1. Demographic and injury-related data of the participants

	<i>M</i>	Range	SD	<i>n</i>	%
Age at injury	24.9	17–50	7.6	76	100
Age at follow-up	38.6	23–62	8.5	76	100
Years since injury	14.1	5.4–25.5	5.5	76	100
Education (years)	11.9	1–19	2.4	76	100
Aetiologies					
Vehicle accidents				48	64
Combat injuries				19	25
Work accidents				9	11
Duration of coma					
30 days and more				21	27.6
8–30 days				26	34.2
1–7 days				13	17.1
less than 24 hours				9	11.8
No coma				5	6.6
No available data				2	2.7
Frequencies* of neurological symptoms					
Sensory disabilities (impaired hearing, vision, hemianopsia)				61	80
Motor disabilities (hemiplegia, quadriplegia, hemiparesis, apraxia, ataxia)				59	77
Epilepsy				19	25
Aphasia				10	13

*The percentages do not add up to 100% as participants exhibit more than one symptom.

rehabilitation programmes and eight did not report on any formal post-acute rehabilitation programmes. Demographic and injury-related data on this group is presented in table 1.

Forty-seven (62%) of the participants were comatose for more than 1 week. Fifty participants (66%) suffered between two and four neurological symptoms after the injury, such as hemiplegia, hemianopia, and aphasia. Data on Glasgow Coma Scale scores were not available for many of the patients who had been injured before the scale was developed or used in Israel.

Tests and procedure

Each subject was interviewed and assessed by a psychology graduate student for ~7 hours, divided into four sessions. The assessment meetings were held either at the Institute or at the participant's home. At the time of the study, 13 (17%) individuals were living with their parents and 49 (65%) with a spouse. Thirty-four of these family members (one family member per participant, eight parents, 26 spouses) agreed and were approved by the participants to complete questionnaires at home or by mail. Demographic and medical data were collected from patient-files. The outcome data was arranged in six domains and collected via an extensive battery of standardized tests and questionnaires, and evaluations by family members.

Psychiatric symptomatology and psychological reactions

These were assessed by the following means:

- (1) The *Symptoms Check List 90 Revised (SCL-90-R)* [18]: A 90-item psychiatric check list that produces nine psychopathology scores and a Global Severity

Index (GSI), which reflects the clinical severity of all symptoms. The scale allows for the comparison of participants' scores to a US normative sample [18]. A large sample of Israeli veterans with and without Combat stress Reaction (CSR) is also available [19].

- (2) A *Post-Traumatic Stress Disorder Inventory*, which consists of 13 statements describing the Diagnostic Symptoms Manual-III (DSM) symptom clusters of Post-Traumatic Stress Disorder (PTSD). The inventory was validated against concurrent inventory scores and clinical interviews of a sample of 114 soldiers, 1 year after the 1982 Lebanon War [19–21]. Based on DSM-III definitions, a probable diagnosis of PTSD was assigned to those persons who fulfilled the four DSM criteria for PTSD: The experiencing of a traumatic event; re-experiencing symptoms; numbing of responsiveness and hyper-arousal symptoms. For the purpose of the present study, endorsement of the symptoms of concentration and memory difficulties was not counted as one of the four criteria, as these symptoms are probably the result of the neurological deficits.
- (3) The *Behaviour Evaluation Checklist* [17]: A 15-item checklist, answered by a family member, that addresses the frequency of occurrence of five dimensions of behaviour: impulsiveness, rigidity, dullness, low frustration level, and aggressiveness. Questions are answered on a scale of 0 ('not at all') to 5 ('very frequently'). Scores range from 0–75 (e.g. 'To what extent does the participant exhibit physical violence' or 'To what extent is the participant unable to modulate his or her behaviour with regard to changing circumstances').
- (4) The '*Acceptance of Disability Questionnaire*' [22]: Includes 41 statements describing different reactions towards the disability. Answered on a scale of 1 ('Disagree completely') to 6 ('Largely agree'). Scores range from 41–241.

Cognitive abilities

These were assessed using the following tests:

- (1) The *Wechsler Adult Intelligence Scale-Revised (WAIS-R; Hebrew version)* [23], full-scale, verbal and performance IQ.
- (2) The *Rey Auditory Verbal Learning Scale (AVLT, Hebrew version)* [24].
- (3) The *Wechsler Memory Test (WMS-R, Hebrew version)* [25], Visual Reproduction sub-test and Logical Memory sub-test.
- (4) The *Purdue Peg-Board test* [26].

Vocational status

This was assessed by four indexes:

- (1) Employed/unemployed index: An 'employed' score was assigned to participants who, at the time of the study, and for at least 3 months prior to it, were employed either in regular employment in the free market, in a family business, in sheltered employment, as volunteers, or as housekeepers. Hence, an 'unemployed' score was assigned to those who manifested no occupational activity whatsoever.
- (2) Indexes of fields and levels of occupation were assigned to the employed participants according to Roe's [27] division of occupations into three levels:

professional, skilled and unskilled, and into eight fields (e.g. technology, outdoor, etc.).

- (3) Index of stability at work was calculated as the function of the potential work period available to the subject since discharge from hospital, the actual time spent at various jobs, and the number of jobs held during that period. The index ranged from 0.0–1.0, with 1.0 indicating maximum stability.
- (4) Source of income—in order to assess the degree of financial independence, the participants were asked to specify their major sources of income on a nominal scale.

Family functioning

This was assessed by the following means:

- (1) The family functioning sub-scale of the Extended ADL Questionnaire [28]. This sub-scale includes four questions concerning the subject's involvement in family life (e.g. 'Do you take part in the family's decisions?'). Answers are scored on a 1 ('not at all') to 5 ('very frequent') scale, with 5 indicating a high level of involvement in family life as perceived by the patient. In order to gauge the family members' evaluation of the participants' functioning in the family, a family member (spouse or parent) completed the same sub-scale.
- (2) Family members also answered the SCL-90-R questionnaire [18] in order to assess their psychological well-being.
- (3) The Burden questionnaire [29] assesses family members' feeling of burden with 25 'yes or no' questions concerning the family members' reactions to their role as caregivers.

Social functioning

- (1) The social activities sub-scale of the Extended ADL questionnaire [28, 30]. This sub-scale includes eight questions regarding the participants' active social involvement (e.g. 'Do you entertain friends at your home?'). Family members completed the same sub-scale.
- (2) Participants and family members were asked to estimate the number of close friends the participants had.
- (3) Participants were asked to assess the extent of their social support network, which was again compared to the same assessment by the family member.

Independence in activities of daily living

This was assessed as follows:

- (1) The 'home activities' and 'independence in mobility' sub-scales of the Extended ADL questionnaire [28, 30]. The home activities sub-scale includes 11 questions (e.g. 'Do you cook by yourself?'). The independence in mobility sub-scale includes 10 questions (e.g. 'Do you manage climbing up the stairs?'). A family member also answered both.
- (2) Type of residence was also reported as an indicator of independence in ADL.

Subjects' socio-demographic background, medical history, education and vocational data

These were collected via questionnaires and structured interviews that were constructed for the purpose of the study and that included 192 informative questions. Either the participant or a family member responded to these, or the participant's medical file was reviewed to gather the information.

Results

The current status of the 76 participants is presented according to the six domains. Where available, the results were compared to normative data and to family members' evaluations. The relations of the cognitive abilities and psychiatric symptomatology with the level of functioning in the other four functional domains were also examined.

Psychiatric symptomatology and psychological reactions

The mean SCL-90-R GSI of the 76 participants was 1.07(SD 0.71), reflecting an overall high level of psychiatric distress when compared to normative data [18]. SCL-90-R sub-scale profile indicated that not all symptoms were equally endorsed. The percentages of participants who obtained scores higher than the 95th percentile, compared to the normative data [18], are presented in figure 1. Significant differences (chi-square) from the expected source frequencies were observed in seven of the nine sub-scales. The hostility, depression and anxiety sub-scale scores were endorsed by more than 40% of the participants above the 95th percentile. The paranoid ideation and interpersonal sensitivity sub-scales were endorsed at normal levels.

The mean GSI of the participants score is also very similar to that obtained by a group of Israeli veterans of the Lebanon War who sustained a combat stress reaction (M GSI = 1.10, SD 0.90, n = 213), and is more than twice as high as that of a group of matched normal Israeli controls (M = 0.43, SD 0.54, n = 116) [19].

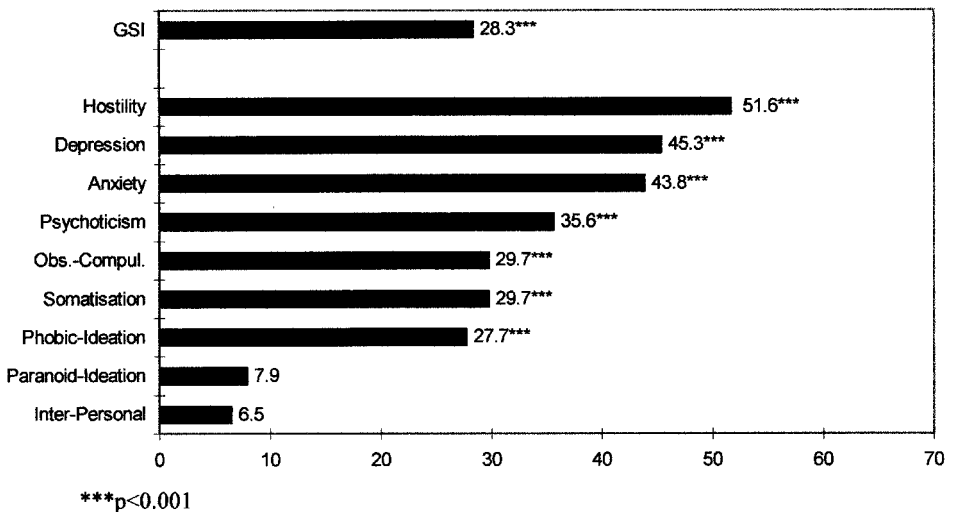


Figure 1. Percentage of patients with significantly elevated SCL-90-R and GSI scores.

Table 2. Pearson correlations between SCL-90-R sub-scales and the scores on the Behaviour Evaluation (BE) and Acceptance of Disability (AD) questionnaires

	Som	Obs	Int	Dep	Anx	Host	Phob	Par	Psych	GSI
BE (n = 34)	0.42*	0.40*	0.34	0.45**	0.51**	0.51**	0.43*	0.40*	0.46**	0.49**
AD (n = 76)	-0.65**	-0.59**	-0.51**	-0.70**	-0.53**	-0.47**	-0.48**	-0.52**	-0.55**	-0.65**

* $p < 0.05$, ** $p < 0.01$ (2-tailed).

Som = Somatization; Obs = Obsessive–Compulsive; Int = Interpersonal Sensitivity; Dep = Depression; Anx = Anxiety; Host = Anger–Hostility; Phob = Phobic Ideation; Par = Paranoid Ideation; Psych = Psychoticism.

Further support for this psychopathological similarity is evidenced by the prevalence of PTSD in this sample, as revealed by the PTSD questionnaire. Of the 68 respondents on this questionnaire, seven (14%) met the full diagnostic criteria of PTSD. Thirteen (19%) of the participants reported re-experiencing symptoms, 42 (62%) reported numbing of responsiveness symptoms, and 48 (71%) reported hyper-arousal and avoidance symptoms.

The participants’ psychiatric symptomatology and GSI scores are also significantly correlated with behaviour disturbances as evaluated by a family member on the Behaviour Evaluation Checklist (BE). Except for Interpersonal Sensitivity, the higher the psychiatric symptomatology, the more behavioural problems are reported (table 2).

A clear pattern of significant negative correlations between all of the SCL-90-R scores and the Acceptance of Disability (AD) score was also found, indicating that the lower acceptance of disability, the higher the psychological symptomatology, and vice versa. The highest correlations obtained were between the AD score and the Depression, Somatization and Obsessive–Compulsive sub-scales (table 2).

Cognitive abilities

Intelligence

The means and SDs of verbal IQ, Performance IQ and Full-Scale IQ were 94.42 (SD 14.02), 86.05 (SD 12.17) and 90.10 (SD 12.61), respectively, indicating an intellectual ability within the low–normal range. A statistically significant eight-point advantage for verbal over performance ability was also found ($t = 5.08$, $p > 0.001$).

A profile of the WAIS-R sub-test mean scaled scores is presented in figure 2. The Digit Symbol, Picture Arrangement and Assembly sub-tests, all three within the Performance scale, show the lowest mean scaled scores.

Memory and learning

The average WMS-R immediate Logical Memory and Visual Reproduction scores were 21.62 (SD 8.33) and 30.74 (SD 7.13), corresponding to the 40th and the 48th percentiles, respectively. Slightly lower normative scores were observed on the delayed trials of these two sub-tests, ($M16.17$ (SD 8.21) and $M 24.09$ (SD 10.03), respectively, both corresponding to the 37th percentile).

A marked deficit in verbal learning was revealed, with an average Rey AVLT total learning score (sum of words recalled on trials 1–5) of more than 1 SD lower than that of age-matched normal controls ($M 39.05$ (SD 9.07) as compared to $M 54.50$ (SD 10.21)) [24]. The TBI participants also exhibited a flat learning

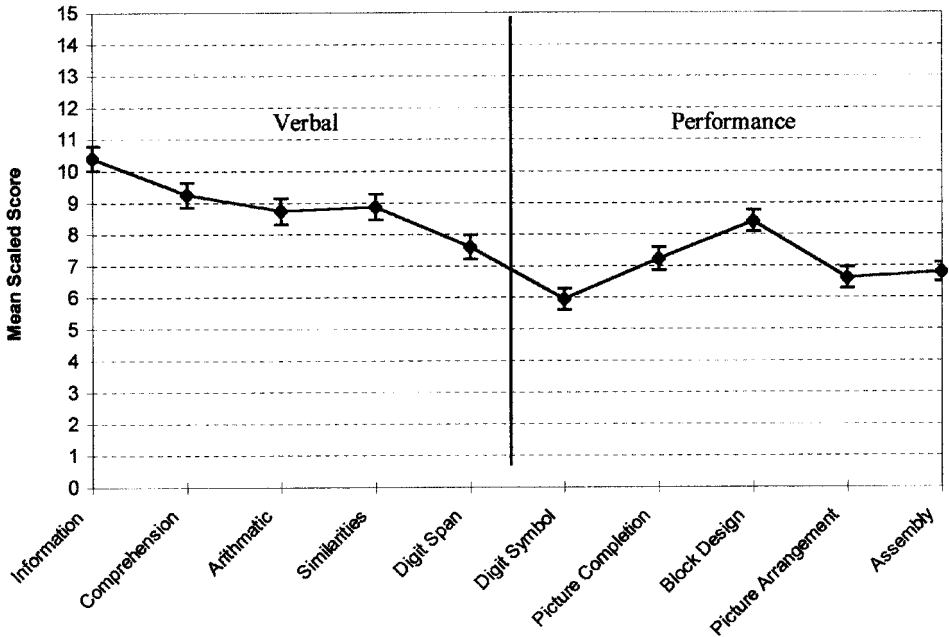


Figure 2. Means of scaled scores and standard errors on the Wechsler Adult Intelligence Scale-Revised sub-tests (n = 59).

curve; however, their performance on the recognition trial was slightly less compromised (11.52 words compared to the expected age norm of 14.13) than delayed recall (6.43 words as compared to the expected age norm of 12.23).

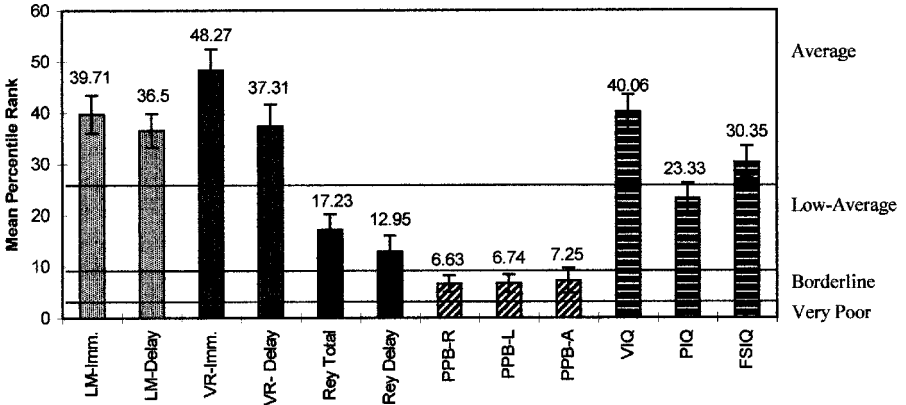
Manual speed and dexterity

These were found to be severely compromised, with performance on the Purdue Peg-Board dominant and non-dominant hands and the assembly procedures more than 2 SD lower than the expected norm (*M* 13.12 (SD 3.04), *M* 12.19 (SD 3.3), and *M* 15.83 (SD 7.25), respectively).

Overall standardized cognitive profile

In order to compare the relative functioning of the participants on the different cognitive abilities, age corrected normative percentile rank scores were generated. The scores of each participant on the WAIS-R, WMS-R and the Rey AVLT were transformed to percentile scores either from age-stratified norms of the test (WMS-R and Rey AVLT) or as a statistical extrapolation of the normal distribution of IQ scores (WAIS-R). The Purdue Peg-Board scores were transformed to percentiles in the same manner, taking into account that the normative sample of that test matches the age range of the participants. The resulting average percentile scores were used to generate a group-profile of cognitive abilities (figure 3).

The cognitive compromise of this group is shown in all the measures, apart from the Immediate Visual Reproduction (WMS-R). The most severely compromised ability was manual speed and dexterity, in which the participants' performance was within the borderline range, followed by verbal learning (Rey AVLT), which was



Note: LM= Logical Memory; VR= Visual Reproduction; Imm. = Immediate; Delay= Delayed Recall; Rey Total = Rey AVLT Sum of trial 1-5; PPB= Purdue Peg-Board; R= Right hand; L= Left hand; A= Assembly.

Figure 3. Mean percentile rank performance and standard errors on neuropsychological tests.

in the low-average range. Less compromised were verbal and figural memory (WMS-R), which were in the lower half of the average range.

Vocational functioning

Forty-six (60.5%) of the participants were employed at the time of follow-up for at least 4 months prior to the study. In comparison, at the time of the study and during the preceding decade, the nation-wide unemployment rate remained below 10%. A majority of 34 (73%) of the employed participants were working in low-level unskilled professions (table 3). The main vocational field was technology (37%). Eighteen of them (39%) were employed in non-competitive jobs, i.e. either in sheltered settings or as volunteers.

An examination of the post-injury vocational history of the participants indicated that 62 (82%) had been employed at least once since the injury. Of these 62 participants, 22 (35%) had held one job, 22 (35%) had changed jobs once, and 18 (30%) had worked in three to five different places since the injury. The index of work-stability ranged between 0.02–1.0, with a mean ratio of 0.28 (SD 0.25). The average employed participant in this study, thus, changed jobs every 3.5 years since the injury. Forty-five (58.6%) of the participants reported that their main source of income was compensatory allowance, only 10 participants (13.7%) reported salary as

Table 3. Frequencies and percentages of occupational level, occupational fields and occupational framework of the 46 employed participants

Occupational level		Occupational field		Occupational framework	
Professional	3 (7%)	Technology	17 (37%)	Competitive	28 (61%)
Skilled	9 (20%)	Administration	11 (24%)	Non-competitive	18 (39%)
Unskilled	34 (73%)	Other	18 (39%)		
Total	46 (100%)		46 (100%)		46 (100%)

Technology=production, maintenance, transportation, appliance repair and operation; Administration=management, clerical and office work; Other=services, businesses, science, art, culture, etc.

the main source, three (4%) relied mainly on family support, and 18 (23.7%) named various combinations of the above as their main source of income. The employed and unemployed participants were compared with regard to their SCL-90-R GSI scores and their WAIS-R Full Scale IQ (FSIQ). Significantly higher GSI scores were observed in the unemployed group (M 1.38 (SD 0.80) as compared to M 0.85 (SD 0.57), $t = 2.81$, $p < 0.01$ equal variance not assumed). The two groups did not differ on their WAIS-R FSIQ scores.

Family functioning

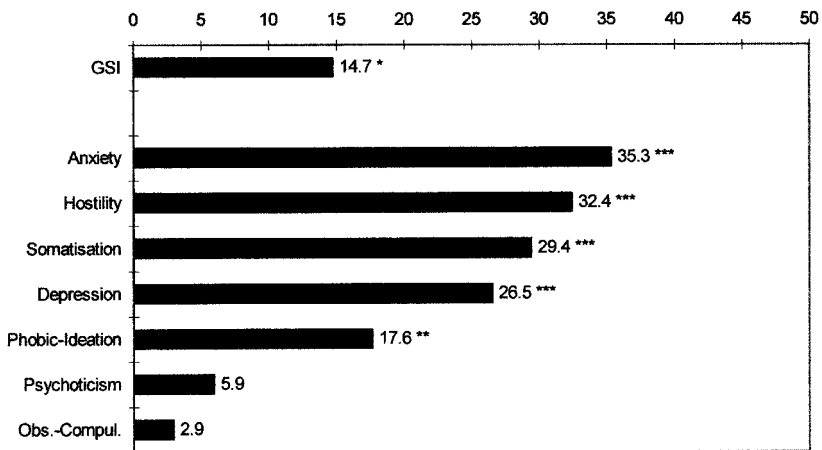
Forty-nine (64.4%) of the participants were married at the time of the study, of which 21 (28%) were already married at the time of the injury. Of the 27 unmarried participants, 18 (66%) had never been married and nine (34%) were divorced. Of the latter group, four (44%) had been married at the time of injury and divorced later. Compared to the 86% national, age-matched prevalence of marriage and 5.9% prevalence of divorced men and women who never remarried [31], these findings indicate that significantly less of the brain-injured participants are married and that the prevalence of divorce among them is higher ($\chi^2 = 6.32$, $p < 0.05$).

Involvement in family life

This was assessed by the responses of participants and family members on the ‘family functioning’ sub-scale of the Extended ADL Questionnaire [28]. The participants’ average score was 3.2 (SD 1.2), corresponding to an evaluation of functioning of medium-to-good, which was also supported by the relatives’ evaluations (M 3.69 (SD 1.02), $t(32) = -1.04$, $p > 0.05$).

Relatives’ psychiatric symptomatology

For family members, the average GSI on the SCL-90 was 0.71 (SD 0.48). The percentages of family members who obtained scores higher than the 95th percentile compared to the normative data [18] are presented in figure 4. Chi-square analysis



* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Note: Paranoid ideation and interpersonal sensitivity were endorsed below the 95 percentile.

Figure 4. Percentage of family members with significantly elevated SCL-90-R and GSI scores.

revealed significant differences from the normative rate on the GSI score and on five sub-scales: Phobic Ideation, Depression, Somatization, Hostility, and Anxiety. No significantly elevated scores were found on the Interpersonal Sensitivity and Paranoid Ideation sub-scales.

Burden

Family members scored an average of 11.2 (SD 5.43) points on the Burden Questionnaire [29]. This score is 0.67 SD higher (i.e. worse) than that reported by these authors among relatives of 44 patients with severe head injuries 1 year after the injury (M 7.14 (SD 6.0)). In order to determine the relationships between perceived family burden and the participants' psychiatric and intellectual deficits, the relatives' burden score was correlated with the GSI and the FSIQ of the participants. The results showed a positive and significant correlation with the GSI, and a non-significant negative correlation with the FSIQ ($r = 0.59$, $p < 0.01$, and $r = -0.33$, $p > 0.05$, respectively).

Social functioning

Participants evaluated the level of their social functioning on the social activities sub-scale of the ADL questionnaire [28, 30] to be low-average (M 2.17 (SD 0.93)). This score was significantly lower than the other sub-scales of this questionnaire, i.e. family, home and mobility ($F = 70.74$, $df=1.62$, $p < 0.001$). Family members' evaluations of the social functioning of the subject were very similar (M 2.21 (SD 1.00); $t(32) = -0.098$, $p > 0.922$) and moderately correlated to that of the participants ($r = 0.49$, $p < 0.01$).

The participants reported having an average of 2.7 (SD 2.62) friends (range: 0–9). Nineteen (31.1%) of them indicated that they have no friends at all outside the family. Family members' estimates were very similar to those of the participants ($r = 0.546$, $p < 0.01$), revealing no significant difference ($t(32) = 0.717$, $p > 0.48$). With regard to the extent of the social support network, participants reported an average of 4.69 (SD 5.59) members in the network, including family members, with five (8.2%) indicating that they had no social support at all, i.e. total loneliness.

Finally, the ADL social functioning sub-scale scores correlated in a negative and significant correlation with GSI ($r = -0.35$, $p < 0.01$) and did not correlate with WAIS-R FSIQ ($r = 0.09$, $p > 0.05$).

Independence in daily living

Forty-nine (64.5%) of the 76 participants shared a residence with a spouse at the time of the present follow-up. Thirteen (17%) lived with their parents, 11 (14.5%) lived alone, and three (4%) shared a residence with a friend. Table 4 presents the status of residence by age group. The data shows the relative scarcity of participants living with a roommate, even among those in their 20s and 30s. It is also noticeable that nine subjects in their 30s and 40s still lived with their parents.

The participants' evaluations of their independence in daily routines were M 3.02 (SD 1.07) on the 'home' activities sub-scale and M 2.98 (SD 0.77) on the 'mobility' sub-scale of the ADL questionnaire. These appraisals were largely corroborated ($r = 0.85$ and $r = 0.75$, respectively, $p < 0.001$) by the relatives' average estimates of 2.83 (SD 1.19) and 2.88 (SD 0.91). These results correspond to an appraisal of medium-to-good in these two areas.

Table 4. Residence status at the time of the study, stratified by age (n = 76)

Age range	With spouse	With parents	With roommate	Alone	Total
20–30	7 (54%)	4 (31%)	0 (0%)	2 (15%)	13 (17%)
31–40	19 (59%)	5 (16%)	1 (3%)	7 (22%)	32 (42%)
41–50	15 (65%)	4 (17%)	2 (9%)	2 (9%)	23 (30%)
51–64	8 (100%)	0 (0%)	0 (0%)	0 (0%)	8 (11%)
Total	49 (65%)	13 (17%)	3 (4%)	11 (14%)	76 (100%)

The 'home' ADL sub-scale scores were found to have a non-significant negative correlation with the GSI and a significant correlation with the WAIS-R FSIQ ($r = -0.24$, $p > 0.05$, and $r = 0.37$, $p < 0.01$, respectively).

Discussion

The purpose of the present study was to broaden and deepen the relatively small amount of knowledge with regard to the very long-term mental and psychosocial outcomes of TBI. The study adds to previous follow-up studies, by encompassing a broad range of six major functional domains, by relying on objective and standardized measurements, or on the ratings of significant others, rather than on subjective reports, and by applying multiple measures for each domain tested.

Psychiatric symptomatology

In keeping with previous findings [32, 33] that many individuals with brain injuries exhibit psychiatric symptoms, three psychiatric symptom clusters can be delineated in this sample. The first, containing the most strongly endorsed symptoms, includes the Hostility, Depression and Anxiety sub-scales. On these three sub-scales, about half of the participants obtained significantly elevated scores. Indeed, hostility, temper outbursts and poor self-control were among the most common complaints of persons with TBI at shorter intervals following their injury [7, 34] and up to a decade later [9, 35, 36]. Depression and anxiety also characterize the emotional symptoms exhibited by individuals with TBI [14, 37]. In a recent study of 100 TBI patients living in the community, at an average of 8 years post-injury, the occurrence of psychopathology was assessed using the Structured Clinical Interview of the DSM-IV [38]. The overall frequency of Major Depression was 61%. Even when prevalence rates were restricted to post-TBI axis I disorders, major depression and anxiety disorders remained the most common psychiatric sequelae in that study. Late onset depression has also been regarded as related to poor psychosocial functioning, a trend that these findings affirmed.

The second group, containing more moderately endorsed symptoms, with approximately a third of the sample receiving significantly elevated scores, consists of Psychoticism, Obsession–Compulsion, Somatization and Phobic Ideation. A full-blown psychotic disorder is considered rare among TBI patients [37]; however, the data show that at least some of the major symptoms associated with it (e.g. thought control, ideation) are quite common. Low incidence rates have also been reported with regard to Obsessive–Compulsive disorder [37]. However, Lezak [39] notes that obsessive–compulsive traits frequently evolve, probably as compensatory strategies,

when mental inefficiency (i.e. attentional deficits and slowed cognitive processing) is a prominent feature of brain injury. It is noteworthy that the most conspicuous cognitive deficits in the study were indeed related to slowed psychomotor reaction and processing speed.

The third group contains the least endorsed symptoms—Paranoid Ideation and Interpersonal Sensitivity—which do not exceed the normal levels of distress. In light of the poor results in the social domain, the lack of subjective reports on these two symptoms may seem odd. It may indicate that the participants' poor social functioning is more related to their increased tendency towards internalized depression and externalized, concrete, hostile behaviours, than to more deeply rooted paranoid ideation and interpersonal distrust. It may also be the result of diminished awareness to paranoid-like behaviours that affect their social surroundings without being recognized by them as a symptom.

As expected, high correlations were observed between the psychiatric symptoms and the Behaviour Evaluation Checklist, indicating that behavioural patterns observed by others are closely related to the psychiatric distress experienced by the person with TBI. The more distressed persons with TBI are, the more they exhibit behavioural disturbances. The results also indicate that these same participants find it harder to come to terms with their disability. The Acceptance of Disability scores correlated negatively with psychiatric symptomatology and, in particular, exhibited a high correlation with depression and somatization. Hence, acceptance of the disabilities is, in this sample, related to a positive, less depressed and less somatically concerned state of mind, whereas unacceptance of the disability is related to elevated psychiatric symptomatology and behavioural disturbances.

PTSD was relatively common among the sample, appearing at a rate of 14%. This is very similar to the 10–20% rates reported in the few long-term studies of chronic PTSD [40], and of combat stress reaction (CSR) 3 years after the war [20]. The profile of PTSD-related symptoms of the participants is also very similar to that found in the longitudinal course of PTSD. Hibbard *et al.* [38] also reported that 19% of their 100 TBI patients suffered from PTSD at an average of 8 years post-injury. The question of the validity of PTSD diagnosis in TBI is extensively debated in the literature [41] and is not the purpose of the present study. However, the frequency of intrusive memories in the sample was similar to that reported in other samples of trauma victims [40], a finding that is not readily explained by the head trauma itself, and that lends support to previous reports on the co-occurrence of the two diagnoses [38, 42].

Cognitive functioning

The overall intellectual functioning of the participants was within the lower range of the average ability. A significant advantage of verbal IQ as compared to performance IQ was also noted. This advantage is probably the result of the general slowing in psychomotor ability and processing speed which were the most pronounced cognitive deficit in this group, and which affects the time-dependent performance scale tests. Lezak [39] also attributed at least some of this slowing of motor responses to compensational strategies employed by the patients, who are aware of their difficulties in processing information. Severe verbal learning deficits were also common in this sample. Previous research regarding the cognitive outcome of TBI at shorter time-intervals also reported compromised mental and motor speed, slowed

thinking and reaction times, and consequent lowered scores on timed tasks [43, 44]. These deficits are characteristic of the diffuse damage that accompanies most TBI [1]. The susceptibility of learning to interference effects, which was observed in the study, is also reported as a characteristic of the memory performance of survivors of TBI [45]. It should be noted, however, that this cognitive profile might be related to clinical pre-selection, with only 13% of the group suffering from aphasia (i.e. severe left hemisphere injuries). The predominance of male participants in the group may also have an effect on the magnitude of the VIQ-PIQ discrepancy [46]. Hence, the generalization of this specific profile to other groups of brain-injured individuals must be taken cautiously.

Objective measurements of cognitive abilities at longer intervals are scarce, and therefore, hard to compare. Significant others rated Sbordone *et al's* [11] patients on the Portland Adaptability Inventory as having mild cognitive deficits. This is replicated in these findings only with regard to general intellectual abilities and memory of well-structured material. However, this group could hardly be described as suffering from mild cognitive deficits with regard to psychomotor speed and learning capacity. The partial discrepancy between the two studies could be explained by differences between the subjective reports of relatives in their study, as compared to the objective measurements of ability in this study. Thomsen's [13] report of memory impairment in all but two of her sample seems to concur with these findings; however, the exact nature of this deficit is not described.

Vocational functioning

The 60% employment rate of the current sample, although lower than the national rate, is higher than the one reported in previous follow-up studies. In contrast to these findings, Dawson and Chipman [16] reported a 25% employment rate in their epidemiological follow-up, of which a third were employed in sheltered or unpaid jobs. This discrepancy may result from the difference between sampling on a clinical basis and community-based sampling. It is interesting to note, however, that the ratio of occupational settings in the two studies is similar, with approximately a third of the working participants employed in non-competitive, sheltered settings. These results are more compatible with those reported by Asikainen *et al.* [15], when matched for age and severity of injury. Their findings, which were based on a clinical sample, indicate similar rates of employment. However, the term they used to assess the vocational status was 'employability'; no data is reported as to the percentage of patients who were actually working at the time of study. Another measure in this study—the index of stability—makes salient the importance of differentiating employability from employment. It demonstrates the participants' difficulties in maintaining a steady job for prolonged periods of time and, hence, their limited chances for advancement at work. It highlights the importance of considering not only the potential for employment but also the rate of accomplishment. Indeed, the average employed participant in this study changed jobs every 3.5 years, a finding that lends support to consideration of instability at work as one of the main obstacles for achieving vocational rehabilitation [47]. The finding of a significant relationship between unemployment and psychiatric symptomatology renders further support for the same trend. Shorter-term outcome studies of severe TBI patients who participate in rehabilitation programmes have generally indicated

an employment rate of 50–65% [48]. The results seem to replicate this trend for the very long-term outcome as well.

The findings regarding the occupational field are also important with respect to the qualitative characteristics of employment. Most of the working participants were employed in the fields of technology or administration. These two fields, especially at their lower levels, involve structured, routine tasks, with little requirement for initiative and creativity. They do not require interpersonal interaction, keeping the need for utilization of social skills to a minimum. It seems that these features make both fields particularly suitable for the vocational rehabilitation of persons with TBI. Indeed, only a small minority of the participants are employed in more creative or socially demanding occupational fields such as arts and entertainment, science or services.

The combination of relatively high unemployment and low occupational level also leads to low levels of income, evident from the fact that only 10 participants indicated their salary as their main source of income. A majority of the participants reported compensatory allowance, either from the veterans' administration or from the National Insurance Institute, as their main source of income.¹ This finding highlights the economic burden of TBI on the families and on society in general.

Family functioning

The marriage rate of 64.4% in this sample is substantially lower than the 86% national rate (controlled for age), while the divorce rate (11.8%) is higher, with four (5.2%) of the divorces occurring post-injury. However, notwithstanding this lower than normal family status, the results point to two seemingly contradictory trends with regard to the participants' functioning within their families. On the one hand, the family status shown in this study is higher than that in previous reports. Tate *et al.* [49] report a divorce rate as high as 54% 6 years after injury. Thomsen [12] reports that only two out of nine married couples remained married at 15 years post-injury. A later report, at 20 years post-injury [13], found only four married participants in a group of 31 patients. Dawson and Chipman [16] reported a 34.4% marriage rate, and 46.5% singles in their epidemiological study. The more positive trend of these findings is further supported by the participants' and their relatives' reasonably positive evaluation of their functioning within the family. On the other hand, family members in this sample reported a high sense of burden, a finding that is compatible with reports suggesting that relatives' stress and sense of burden increase over time [7, 29, 50]. This parity between the relatively positive evaluation of the patient's family functioning and the increased sense of burden may be the result of a process of realization of expectations. Family members of persons with TBI whose injuries occurred over a decade ago may have adjusted their level of expectation from their injured partners, and are, thus, relatively satisfied with how their family functions, even though their own sense of burden is still high. The significant correlation between the relatives' sense of burden and the participants'

¹ Fifty participants (66%) in our sample were army veterans. These participants usually receive compensatory allowance from the Ministry of Defence at least at the rate of an average salary. The National Insurance Institute referred 34% of the participants. Their compensatory allowances are in many cases equal to or lower than the minimum wage. Even so, no differences were found in the rates of employment, stability at work and family status between the two groups.

GSI scores also supports this interpretation. It seems that the more disturbed participants cause more of a sense of burden, even though they are evaluated by members of their families, as a group, as behaving within the expected range. Note also that the relatives' burden was related only to the psychiatric symptoms of the participants, not to their intellectual abilities. A similar pattern of self-reported positive quality of life, together with high levels of strain felt by relatives, has indeed been reported recently in a 10-year follow-up study by Koskinen [51].

The data regarding the psychiatric status of family members suggest an overall moderate level of distress, with ~15% displaying a significantly elevated level beyond the 95th percentile. Scores on four sub-scales were particularly high: anxiety, hostility, somatization and depression. A recent study by Gervasio and Kreutzer [52] used the Brief Symptom Inventory (a shorter version of the SCL-90-R) to assess levels of psychiatric distress among family members. Just under 25% of their participants showed clinically elevated GSI scores, but the pattern of symptom profile displayed by their group only partially resembles this one. Hostility and Anxiety were found to be amongst the highest scales endorsed by relatives in both studies, but large differences in the results for other symptoms were also revealed, presumably reflecting differences in the time elapsed since the injury. In Gervasio and Kreutzer's study, the vast majority of participants were relatives of persons injured up to 4 years earlier.

Social functioning

Participants and family members evaluated their social functioning at the lowest level, as compared to the other functional domains. Indeed, 31% of them reported that they had no friends at all, and 8% reported complete social isolation. Previous studies also point to the social domain as a major source of distress. Thomsen [13] found that 19 (61%) of her patients had no friends or acquaintances, but had contact with one or more family members. Similarly, Dawson and Chipman [16] found that 27% of their participants never socialized with family or friends at home, 45% never talked on the phone and 76% never attended social activities such as films and sporting events. In contrast, Shordone *et al.* [11] found only mild social integration difficulties, even for the most severely injured persons 10 years post-injury. Unsurprisingly, the results also indicate that the social functioning of participants was significantly related to their psychiatric status and not to their intellectual abilities.

Independence in daily living

About 65% of the participants in the study lived with a spouse, only 14% lived alone and non lived in nursing homes or special institutions. This contrasts with Thomsen's [13] report of only four participants out of 31 living with a spouse, 15 living alone and eight living in nursing homes. Seventeen per cent of the participants were still living with their parents, including nine between the ages of 30–50, a figure not much lower than that of Thomsen's report. In addition, only three of the participants lived with a roommate, a finding that may reflect the interpersonal difficulties of persons with TBI. The discrepancies between these findings and those of Thomsen may reflect cultural differences in coping and attitudes towards disability or differences of sampling. The participants appraised themselves as relatively independent in domestic activities and in the motor and

locomotive domain. These appraisals were largely corroborated by family members and were significantly related to the participants' intellectual abilities and not to self-reported psychiatric symptomatology. This seems to indicate that physical impairment and locomotion disabilities do not constitute major areas of practical and emotional concern for these patients at the very long-term post-injury. Dawson and Chipman [16] found that 66% of their respondents reported the need for ongoing assistance with some tasks of daily living, but only 36% required assistance in physical tasks on a daily basis. A similar pattern was revealed in Thomsen's [13] study, with two-thirds of her sample having normal or moderate disability in walking ability, in spite of the grave severity of injury that characterizes that group. Sbordone *et al.* [11] reported significant improvement on both ambulating and use of hands, as retrospectively evaluated by relatives. At 10 years, even the most severely injured persons in their study reported only a mild level of severity in this domain. Thus, the data support and replicate previous findings, wherein domestic ADL and locomotion are considered a less prominent disability at the very long range post-injury.

Summary and conclusions

It is evident from these results that the TBI participants frequently suffer from permanent difficulties in all areas of their lives. The findings also point to differences between and within domains that enable the delineation of a profile of less disabled versus more compromised domains, and a comparison to previously reported outcome reports. The resulting profile indicates primarily severe long-term psychiatric problems. In this as well as previous studies, depression, anxiety and hostility are among the most conspicuous symptoms. Similar rates of Obsessive Compulsive Disorder and PTSD symptoms were also found. In addition, the results point to higher than previously reported rates of psychoticism and paranoid ideation. It was also added that psychiatric symptomatology is related to objective measures of behaviours (i.e. relatives' reports) and that unacceptance of the disability is related to depression and psychiatric symptomatology. Secondly, the results are in accordance with previous findings of short-term follow-ups with regard to psychomotor slowness and difficulties in information processing. The present study contributes further, by showing that these specific disabilities, which were previously reported at shorter post-injury terms, are sustained in the long-term. The employment rate among the participants was higher than previous reports. To that was added a deeper analysis of the qualitative aspects of employment and work habits. Low-level technological and clerical professions were found to be the most frequent fields of employment. Stability at work was found to be low. The present study found somewhat higher rates of marriage and lower rates of divorce than previously reported, but both were different from the age-controlled national rates. In accordance with previous reports, parity was also found between a fairly good evaluation of the participants' functioning within the family and high levels of burden as reported by family members. This parity was explained in terms of adaptation of expectations. Previous studies, as well as this one, found long lasting loneliness and social withdrawal to be a major problem in the lives of persons with TBI. In contrast, physical independence and ADL functioning were repeatedly assessed as quite reasonable at the very long-term post-injury stage.

Of the four functional areas studied, vocational, family, social functioning and independence in ADL, the first three were found to be related to psychiatric symptomatology and not to intellectual abilities, whereas only independence in ADL was related to IQ and not to symptomatology. Evidently, this was also the less compromised domain. Hence, these results lend support to the conception that long after injury the main sources of disabilities are related more to psychiatric and behavioural symptoms than to cognitive aptitudes and abilities.

From a clinical point of view, the findings shed light on a possible need for long-term, continued aid, mainly in the domains of (1) emotional reactions, both of the identified patients and their family members, (2) the vocational domain, with regard to potential unemployment, low level of employment and attendant financial problems, and (3) in the social domain with regard to potential isolation, withdrawal and narrow support networks. TBI, according to these results, is not only a long-term disability but also a long-term goal for rehabilitation. Further outcome studies at this long span are needed in order to validate and generalize this profile of more or less compromised domains. Prospective follow-up studies, using within-participants, repeated measures designs, should be preferred in order to accomplish this goal.

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