ORIGINAL REPORT

FACTORS ASSOCIATED WITH LONG-TERM FUNCTIONAL AND PSYCHOLOGICAL OUTCOMES IN PERSONS WITH MODERATE TO SEVERE TRAUMATIC BRAIN INJURY

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Objective: To examine factors impacting long-term functional and psychological outcomes in persons with moderate-severe traumatic brain injury.

Methods: A prospective cross-sectional study (*n* = 103) assessed the long-term (up to 5 years) impact of traumatic brain injury on participants' *current* activity and restriction in participation using validated questionnaires.

Results: Participants' median age was 49.5 years (interquartile range (IQR) 20.4–23.8), the majority were male (77%), and 49% had some form of previous rehabilitation. The common causes of traumatic brain injury were falls (42%) and motor vehicle accidents (27%). Traumatic brain injury-related symptoms were: pain/headache (47%), dizziness (36%), bladder/bowel impairment (34%), and sensory-perceptual deficits (34%). Participants reported minimal change in their physical function and cognition (Functional Assessment Measure: motor (median 102, IQR 93–111) and cognition (median 89, IQR 78–95)). Participants were well-adjusted to community-living; however, they reported high levels of depression. Factors significantly associated with poorer current level of functioning/well-being included: older age (≥60 years), presence of traumatic brain injury-related symptoms, a lack of previous rehabilitation and those classified in "severe disability categories" at admission. Caregivers reported high levels of strain and burden (55%).

Conclusion: Cognitive and psychosocial problems are more commonly reported than physical disability in the longer-term. A greater focus on participation and ageing with disability in these persons is needed.

INTRODUCTION

Traumatic brain injury (TBI) is the leading cause of death and disability in young people (age < 30 years), affecting 1.5 million persons annually (1). TBI severity ranges from concussion to persistent vegetative states (VS) and minimal conscious state (MCS), and can be categorized as mild, moderate and severe (2). In 2008, there were 2,493 new cases of TBI in Australia, with a total cost of $8.6 billion (3, 4). The lifetime costs per incident case of severe TBI were estimated at $4.8 million across Australia (4). The leading causes of TBI are motor vehicle accidents (50%), falls (21%), violence (12%), sports and recreation (10%) (5, 6).

The overriding objective of trauma care has now extended beyond survival and acute management to reintegration of the patient into home and community (2). With advances in medical care, the survival rates and functional outcomes following TBI have improved dramatically. Despite these treatment options, TBI survivors often have long-term physical, cognitive and behavioural disabilities, residual neurological deficits, medical complications and lifestyle consequences (2, 4), which may limit their everyday activities and participation (6). It is estimated that 40% of those hospitalized with non-fatal TBI sustain impairments that lead to long-term disability (7).

Persons after TBI can present with various combinations of problems. Based on the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) framework (8), the impact of TBI may include: impairments (e.g. motor and sensory dysfunction, pain, balance difficulties, spasticity, memory impairment), which in turn result in activity limitation (mobility, self-care, cognition) and a restriction in participation with society (e.g. impaired social and coping skills, apathy, unemployment, difficulty maintaining interpersonal relationships, driving, managing finances, social isolation, poor self-esteem). The issues of psychosocial adjustment and societal reintegration progress over time and are usually more disabling than the residual physical deficits

(2). These can have a significant economic impact in terms of delayed return to work and/or normal activities and health service utilization. In addition to health-care services, patients with TBI frequently receive costly disability support services (case management, individual therapy support, learning and life skills development programmes). The caregiver burden and associated care costs are also significant (9).

In recent years, the evidence for the effectiveness of post-acute rehabilitation in improving functional outcomes after TBI is increasing (10–12). The ultimate goal of TBI rehabilitation is to help patients resume meaningful participation in their communities and social environments, regardless of whether specific impairments can be eliminated (13). The collection of long-term outcome data is necessary to establish the impact of trauma; to evaluate treatment approaches and to improve trauma care and public health programme planning (14). Moreover, participation issues are important for clinical purposes, programme evaluation, marketing and accreditation and also are the "bottom line" in terms of long-term costs of care, impact on society and quality of life for the patients and their caregivers (15, 16). Therefore, assessing the long-term outcomes, especially participation, is a recognized goal of TBI rehabilitation (7). Despite the existence of various existing surveillance systems (such as trauma registries, hospital admission data-sets) (14, 17), data on longer-term outcomes for TBI (particulary in non-compensable patients in the public health system) is patchy and little is known about community integration programmes in the chronic phase (>2 years) after the initial injury. A series published by a single research group in Melbourne, Australia examined long-term aspects of post-injury changes in outcomes at 2, 5 and 10 years following TBI (17–19). These studies reported that at 10 years post-injury, although mobility outcomes had improved in 75% of the patients, with few participants requiring aids, approximately 40% of patients required more support than before their injury (17). Issues which were prominent included fatigue and balance problems, concerns with communication and cognitive, behavioral, emotional, relationship challenges. Problems that were evident at 2 years post-injury persisted until 10 years post-injury (17). Another study conducted pathway analysis of a sample of patients with severe TBI to explore the causal, predictive relationships that affect outcomes after TBI. This study suggested that cognitive status and pre-morbid status were important predictors of outcomes and that these factors may be more important than injury severity for longer-term outcomes such as participation (20). These studies, however, were mainly conducted in compensable, usually young, patient cohorts in the private healthcare system. These patterns of outcome data therefore cannot be extrapolated or generalized to the non-compensable patient cohorts within the public healthcare system, in Victoria Australia. Furthermore, there is limited data on carer strain and the burden in terms of their family life/relationship, work/finance and recreation associated with caring for persons with TBI. There is an increasing consensus on the importance and crucial role of caregivers in patient management and their positive impact on patients' well-being (21, 22). Previous studies suggest that caregivers of TBI persons with behavioural, cogni-

tive and functional difficulties report high levels of caregiver strain, which correlated directly with caregivers own status in terms of lower quality of life (QoL) and higher levels of psychological and emotional distress (22, 23).

The aim of this study was to examine factors associated with residual TBI-related disability and restriction in participation over a longer-term, including functional outcomes, psychosocial sequelae and participatory domains (independent living, societal integration and health-related QoL) in a community cohort of moderate-severe TBI survivors (non-compensable within the public healthcare sytem of Victoria, Australia). The secondary aim included an assessment of caregiver stress and burden.

METHODS

Design and setting

This prospective cross-sectional study was part of a rehabilitation outcomes research programme for TBI survivors at the Royal Melbourne Hospital (RMH), a tertiary public, government-funded trauma centre in Victoria, Australia, and was approved by its ethics committee (HREC No. 2013.009). All consecutive non-compensable patients registered in the RMH Trauma Database from 1 July 2009 to 30 June 2010 ($n = 827$) were screened for inclusion in the study following a trauma episode. The timing of the assessments was made so as to allow for natural recovery and the completion of acute medical and acute rehabilitation phases. It would be anticipated that the patient would have fully resumed previous functioning and social roles by this time of the assessment.

Participants

All eligible patients in the database were screened, contacted by post and invited to participate in this project by an independent project officer. A follow-up phone call was made to ensure the invitation was received and those who returned signed consent forms were recruited. The criteria for inclusion were: confirmed diagnosis of TBI with major trauma criteria for Victoria with initial Injury Severity Score (ISS) > 15 using Abbreviated Injury Scale (AIS 98; maximum score is 75) admission to an intensive care unit or high-dependency area for > 24 h and require mechanical ventilation; and/or urgent surgery for intracranial, intra-thoracic, or intra-abdominal injury, or for fixation of pelvis or spinal fracture (within 48 h); ≥ 18 years, ability to communicate in and understand English, and ability and willingness participate by giving informed consent or by legal proxy. The main caregivers of these participants were included wherever possible. A caregiver was defined as a person who provides the person with TBI "with the most care and assistance" (24). The primary researcher further explained the study to all participants and/or caregivers.

Procedure

All eligible patients ($n = 236$) based on selection criteria were contacted by post and invited to participate in this project by an independent project officer. A total of 103 patients returned signed consent forms and were recruited for the study. Attempts were made to re-contact the non-responders by telephone. A primary independent research officer contacted the participants (and/or their caregivers) to explain the study and organize the interview appointments. All interviews and assessments (45 min each) were conducted by two independent trained physicians and one research assistant (in clinic or at patients' homes, according to patient preference) using a structured format, over a 6-week period. Wherever possible, caregivers were also interviewed at the same time in a separate room. Data were collected using specific data collection forms and included: demographic and medical information, cognitive and functional ability assessment and health-related QoL measures using standardized instruments (see Measures). The

assessors did not prompt patients, but provided assistance for those who had difficulty with completing the questionnaires. Appropriate rest breaks were provided during these interviews. All assessments were secured and filed, and opened at the time of entry into the database by an independent data entry officer.

Measurement

Participant socio-demographic and TBI-related information (drug use, psychiatric history), injury-related information (date, type and injury code, co-morbidities, Glasgow Coma Scale (GCS) and post- traumatic amnesia (PTA) scores (if available) were recorded following clinical examination and interview. This information was checked against patient medical record, therapy registers and caregiver report.

Global outcomes. The Glasgow Outcome Scale-Extended (GOS-E) (25), an extended revision of the GOS, assesses the functional outcomes in 8 categories: dead, vegetative state, severe disability (low and upper), moderate disability (low and upper) and good recovery (low and upper).

The *Functional Assessment Measure (FIM-FAM)* (26), a 30-item scale combining the Functional Independence Measure (with 13 motor and 5 cognitive items) and FAM with 12 items on cognitive, behavioural, communication, and community function, was used to assess function (activity), cognitive impairment and need for assistance (physician-assessed and discussed with a multidisciplinary rehabilitation team). Rasch analyses of FAM items at rehabilitation admission correlate significantly with indices of injury severity. FAM's reliability in trained staff is reported to be 80% or better (27).

The *Cognitive Log (COGLOG)* (28) a 10-item scale, scored from 0 to 3 for a total possible score of 30, was used to assess cognitive function. The Cog-Log can predict outcome at one year after injury in the neuropsychological domains of attention, executive functioning, and visuomotor-visuospatial abilities after controlling for demographics and injury severity. It has high reliability (Cronbach's alpha 0.74–1.0) and overall internal consistency (0.77).

The 20-item *Centre for Epidemiologic Studies Depression (CES-D)* (29, 30) was used to assess depressive symptoms, with a total score ranging from 0 to 60 (higher scores indicating more depressive symptoms). The CES-D shows excellent internal consistency (Cronbach's alpha > 0.85) and test-retest correlation ($r > 0.5$).

Health-related quality of life and health status outcomes. The 15-item *Community Integration Questionnaire (CIQ)* (31) was used to assess effective role performance in 3 domains: home integration, social integration (outside home) and productivity (work or volunteer activities). Subscale scores were summed across domains with a total score of 29 (higher scores represent greater community integration). CIQ has good internal consistency, with Cronbach's alpha ranging between 0.76 and 0.84.

The *Community Integration Measure (CIM)* (32) comprises 10 declarative statements, which assess perceived community integration in 4 domains: general assimilation, supports, occupation and independent living. Respondents rated each statement on a Likert scale (1 = always disagree, 5 = always agree) with a total score ranging from 10 to 50 (higher scores indicate greater community integration). The CIM has good internal consistency (Cronbach's alpha 0.79–0.83).

The 5-item *Satisfaction With Life Scale (SWLS)* (33) was used to assess QoL, and was completed by the participants using a 7-point Likert scale (0 = strongly disagree, 7 = strongly agree). The internal consistency of the SWLS and Cronbach's alpha is high, exceeding 0.80.

Caregiver-related outcomes. The 13 item *Caregiver Strain Index (CSI) score* (34) was used to assess stressful aspects of care giving (e.g., inconvenience, confining). The caregiver indicated how stressful each identified item was by utilising a Likert rating range from 0–4 (0 = no strain at all, 4 = extreme strain).

The *Caregiver Self-Reported Burden (SRB) of Care* (35) a single visual analogue scale scored in mm along a 10-cm line (score range

0 –100), assessed caregivers' current burden on caring for the patient (higher score indicates greater subjective caregiver burden).

Statistical analysis

Outcome variables included all summary scales (indicated above) and their subscales. A series of analyses were conducted to describe the current level of function, psychological well-being and participation of participants and to identify those factors associated with scores on these scales. Given the skewed distributions, continuous predictor variables (age) were split into 3 subgroups (≤36 years, 37–59 years and ≥60 years) to form approximately equal groups for comparison, and non-parametric analyses (Mann-Whitney *U*, Kruskal–Wallis tests) were used to compare scores across groups. A substantial number of univariate analyses were conducted and to reduce the likelihood of Type 1 errors a *post hoc* analysis was conducted for between-group pairwise comparisons (those with and without impairments) using a Bonferroni adjustment for multiple comparisons (dividing alpha level of 0.05 by the number of tests). With Bonferroni adjustment, the significant level was set at $p < 0.0045$ (0.05/11 tests). This was consistent with the descriptive nature of the study to ensure all potentially important predictors of the long-term sequelae of TBI were identified. All data were entered twice to avoid errors on data entry. Statistical package SPSS 22.0 for Windows was used for all analyses.

RESULTS

Sample characteristics

Of a total of 236 eligible patients, 103 participants consented and were recruited. Fifty-two subjects were not contactable or had moved to another address, 9 were deceased and 72 declined to participate due to family, transport and financial reasons. The median age of participants ($n = 103$) was 49.5 years (interquartile range (IQR): 20.4–23.8), and the majority were male (77%). Less than half (48.5%) had some form of previous rehabilitation and 31 participants (30.1%) had caregivers. Just over half (50.5%) were taking medications related to TBI and/ or other comorbidities. The most common cause of TBI was falls (42%), followed by motor vehicle accident (27%). The majority of injuries were due to blunt trauma (93%), accidents were the cause of injury in over two-thirds (80%) of the sample, followed by work-related events. Participants had a median GCS of 8 (IQR 6–10) and median ISS of 22 (IQR 17.8–26) at admission to the ward. Approximately 90% participants sustained fractures of extremity and/or pelvis and 62% with facial and chest injuries. At the time of assessment, the majority of participants seemed to have recovered well: GOS-E ("Good recovery": Upper 31%, Low 11%); however, one-third fell into the "severe disability" category (Upper: 27%, Low 8%). (Table I) Compared with their younger counterparts (both ≤36 and 37–59 years age subgroups), older participants (≥60 years) were represented less in the GOS-E "Good recovery" category (20.9% vs 39.5% for both younger groups). This result was not statistically significant ($p = 0.17$). (GCS and PTA scores in the database were deemed unreliable due to a number of missing values, and hence were not analysed).

Participant-reported symptoms/impairments

The most prominent symptoms following TBI as reported by the participants were pain and headache related to TBI ($n = 48$,

Table I. *Demographic and clinical characteristics of the sample (*n = 103*)*

Characterisitics	
Age, years, median (IQR)	49.5 (20.4, 23.8)
Sex, male, *n* (%)	79 (76.7)
Caregivers (parents/spouse), *n* (%)	31 (30.1)
Previous rehabilitation, *n* (%)	50 (48.5)
Inpatient	18 (17.5)
Outpatient	39 (37.9)
Current rehabilitation types, *n* (%)	
Hydrotherapy	8 (7.8)
Gym	19 (18.4)
Vocational	2 (1.9)
Physiotherapy	31 (20.4)
Occupational therapy	14 (13.6)
Social worker	6 (5.8)
Dietitian	10 (9.7)
Speech therapy	10 (9.7)
Medical review by GP	20 (19.4)
Currently on prescription medication, *n* (%)	52 (50.5)
Symptoms/impairments, *n* (%)	
Headache	48 (46.6)
Pain	48 (46.6)
Dizziness	37 (35.9)
Bowel/bladder impairment	35 (34.0)
Sensory-perceptual deficit	35 (34.0)
Paresis	32 (31.1)
Falls risk	32 (31.1)
Spasticity	30 (29.1)
Visual impairment	27 (26.2)
Dysphasia	23 (22.3)
Seizures	13 (13.6)
Cause of event, *n* (%)	
Falls	43 (41.7)
MVA	29 (28.2)
Cyclist	11 (10.7)
Assault/violence	11 (10.7)
Other	9 (8.7)
Injury type, *n* (%)	
Blunt injury	96 (93.2)
Penetrating injury	4 (3.9)
Other	3 (2.9)
Type of event, *n* (%)	
Accident	82 (79.6)
Work-related	11 (10.7)
Assault	8 (7.8)
Other	2 (1.9)
GOS-E, *n* (%)	
Low severe disability	8 (7.8)
Upper severe disability	28 (27.2)
Low moderate disability	16 (15.5)
Upper moderate disability	8 (7.8)
Low good recovery	11 (10.7)
Upper good recovery	32 (31.1)

IQR: interquartile range; GOS-E: Glasgow Outcome Scale – Extended; GP: general practitioner; Md: median; MVA: motor vehicle accident; *n*: total number; SD: standard deviation.

Table II. *Descriptive statistics for measurement scales (*n = 103*)*

Scales (range)	Score Median (IQR)
FIM-FAM motor (16–112)	102 (93, 111)
Self care (7–49)	46 (43, 49)
Bowel/bladder (2–14)	14 (12, 14)
Locomotion (7–49)	42 (39, 49)
FIM-FAM cognition (Md, IQR) (14–98)	89 (78, 95)
Communication (5–35)	35 (30, 35)
Psycho-social (4–28)	24 (19, 27)
Cognition (5–35)	32 (26, 35)
FIM-FAM ADL Index (6–42)	36 (22, 39)
CIM Total (10–50)	46 (35, 49)
CIQ Total (0–29)	16 (11, 18)
Home (0–10)	4 (1, 6)
Social (0–12)	9 (7, 11)
Productivity (0–7)	2 (0, 7)
COGLOG Total (0–30)	27 (21, 29)
CESD Total (0–60)	18 (12, 28)
SWLS Total (7–35)	24 (11, 30)
CSI Total (*n*=31) (0–52)	7 (4, 35)
SRB (Carer) (*n*=31) (0–100)	80 (40, 90)

CES-D: Centre for Epidemiologic Studies Depression; CIQ: Community Integration Measure; CIQ: Community Integration Questionnaire; COGLOG: Cognitive Log; CSI: Caregiver Strain Index; GOS-E: Glasgow Glasgow Outcome Scale – Extended; FIM-FAM: Functional Assessment Measure; IQR: interquartile range; n: total number; SRB: Caregiver Self-Reported Burden; SWLS: Satisfaction With Life Scale.

Current level of functioning, participation, psychological well-being and quality of life

Participants reported minimal change to their physical function and cognition, as indicated by high FIM-FAM motor (median 102, IQR 93–111) and cognition (median 89, IQR 78–95) subscale scores. The majority of participants reported some difficulty with their daily activities (FIM-FAM ADL Index median 36, IQR 22–39), and minimal change in their general cognitive abilities, as indicated by high Cognitive Log (COGLOG) scores (median 27 (IQR 21–29). Most participants did report high levels of depression (total CESD, Md; 18, IQR 12–28) with just over half (*n*=52, 51%) having scored equal to or more than the cut-off score of 16 (36), which indicates a higher risk for clinical depression (Table II).

The study participants reported adjustment to community living after TBI (CIM total median 46, IQR 35–49). However, the scores for the composite CIQ, "total" score (median 16, IQR 11–18), "home integration" (median 4, IQR 1–6), and "productivity" (median 2, IQR 0–7) scales were positively skewed, which reflects a negative impact of TBI on participants' social roles and community integration, particularly in these domains (Table II).

Caregiver strain

High levels of caregiver strain (CSI score ≥7) were identified in more than half of the caregivers (*n*=17, 55%). The total CSI rating scores ranged from 1 to 52 with a median of 7 (IQR 4–35). Caregivers rated items such as the person with TBI displaying upsetting

47%), followed by dizziness (*n*=437, 36%). Other common impairments included: sensory-perceptual deficit (34%), falls risk (31%), paresis (31%), spasticity (29%), dysphasia (22%) and seizures (14%). Reports of bladder/bowel dysfunction (urinary urgency/frequency and constipation) were higher than expected (34%) (Table I).

behaviours and emotional adjustments and family adjustments due to disrupted routine as causing "severe" strain. The median score on the caregiver SRB scale was 80 (IQR 40–90), which indicates a high level of burden from the demands of caregiving (Table II).

Factors associated with current level of functioning and well-being

A series of univariate analyses (comparing those with and without impairments) were conducted to identify predictive factors associated with current levels of functioning, participation, and well-being.

Current symptoms/impairments. There was a significant difference in various scales across the most common impairments reported by the participants (Table III). Participants reporting any TBI-related symptoms recorded higher scores on most of the subscales, which indicate significant long-term impact of these symptoms in current health status. Significance level after Bonferroni adjustment (adjusted significant level of $p < 0.0045$) was still achieved for many participant-reported impairments on most scales, particularly those who reported seizures, headaches, pain, bladder/bowel dysfunction and sensory-perceptual deficits. In general, men with TBI-related symptoms at assessment had lower functioning and QoL scores than those without TBI-related symptoms across the outcome measures.

Demographic and disease factors. Participants' sex effects were not seen for any outcome measures except FIM-FAM motor ($p < 0.05$). Demographic variables mediated CIQ scores. Scale scores were compared by splitting the cohort into 3 groups (≤ 36, 37–59 and ≥ 60 years). There were no significant differences in any of the scales except the SWLS total ($p = 0.39$), which indicates that older subjects were significantly satisfied with their current life. Individuals who

Table IV. *Demographic and clinical variables associated with the participant reported outcome measures* (n = 103)

Outcome measures	Sex	Age groups[a]	Previous rehabilitation	Event type	GOS-E[b]
FIM-FAM motor	0.050*	0.883	**0.002***	0.650	**0.000***
Self care	0.108	0.865	**0.001***	0.572	**0.000***
Bowel/bladder	0.055	0.757	**0.009***	0.288	**0.000***
Locomotion	0.113	0.876	**0.003***	0.591	**0.000***
FIM-FAM cognition	0.806	0.809	**0.008***	0.457	**0.000***
Communication	0.284	0.791	**0.003***	0.460	**0.000***
Psycho-social	0.553	0.909	**0.007***	0.379	**0.000***
Cognition	0.694	0.957	**0.015***	0.476	**0.000***
FIM-FAM ADL Index	0.605	0.648	**0.008***	0.744	**0.000***
CIM Total	0.891	0.584	0.242	0.124	**0.000***
CIQ Total	0.137	0.119	0.255	0.527	**0.000***
Home	0.123	0.850	0.106	0.159	**0.000**
Social	1.00	0.128	0.267	0.685	**0.000***
Product	0.283	0.125	0.113	0.852	**0.000***
COGLOG Total	0.405	0.345	**0.001**	0.524	**0.000***
CESD Total	0.217	0.742	0.167	0.333	**0.000***
SWLS Total	0.315	**0.039***	**0.020***	0.620	**0.000***

*Values significant at 0.05 level (shown in bold).
[a]Age groups: ≤ 36, 37–59, ≥ 60 years; [b]GOS-E categories: Severe disability, Moderate disability, Good recovery. CES-D: Centre for Epidemiologic Studies Depression; CIQ: Community Integration Measure; CIQ: Community Integration Questionnaire; COGLOG: Cognitive Log; CSI: Caregiver Strain Index; GOS-E: Glasgow Glasgow Outcome Scale-Extended; FIM-FAM: Functional Assessment Measure; SRB: Caregiver Self-Reported Burden; SWLS: Satisfaction With Life Scale.

received previous rehabilitation showed significantly better scores on all FIM-FAM subscales, COGLOG total and SWLS total scores, which implies that any type of previous rehabilitation improved patients' physical and cognitive function and QoL. There were

Table III. *Comparison of outcomes for participants with and without impairments/symptoms* (n = 103)

Outcome measures	Symptoms/impairments*										
	Dysphagia	Paresis	Seizures	Headache	Visual impairment	Dizziness	Falls risk	Spasticity	Pain	Bladder/ bowel dysfunction	Sensory-perceptual deficit
FIM-FAM motor	0.006	0.011	**0.000**	**0.000**	0.004	0.003	0.001	0.026	**0.000**	**0.000**	**0.000**
Self-care	0.029	0.041	**0.003**	**0.000**	0.020	0.012	0.005		**0.000**	**0.000**	**0.000**
Bowel/bladder	0.003	0.003	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**	0.005	**0.000**	**0.000**	**0.000**
Locomotion	0.040	0.011	**0.002**	**0.000**	0.019	0.019	0.011		**0.000**	**0.000**	**0.000**
FIM-FAM cognition	0.002	0.001	**0.000**	**0.000**	0.001	0.017	0.003	0.008	**0.000**	**0.000**	**0.000**
Communication	0.017	0.039	**0.003**	**0.000**	0.015		0.038		**0.000**	**0.000**	**0.000**
Psycho-social	0.005	0.002	**0.000**	**0.000**	0.001	0.023	0.005	0.008	**0.000**	**0.000**	**0.000**
Cognition	0.002	0.002	**0.000**	**0.000**	0.001	0.013	**0.003**	0.013	**0.000**	**0.000**	**0.000**
FIM-FAM ADL Index	0.004	0.004	**0.000**	**0.000**	0.001	0.004	**0.001**	0.002	**0.000**	**0.000**	**0.000**
CIM Total	0.008	0.003	**0.000**	**0.000**	0.005	0.044	0.011	0.016	**0.000**	**0.000**	**0.000**
CIQ Total			0.024	**0.000**					**0.000**	**0.000**	**0.000**
Home			0.033	**0.000**					**0.000**	**0.000**	**0.000**
Social	0.017	0.030	0.010	**0.000**		0.023			**0.000**	**0.000**	**0.000**
Product									**0.003**	**0.003**	**0.000**
COGLOG Total	0.003	0.004	**0.000**	**0.000**	0.001	0.022	0.004	0.009	**0.000**	**0.000**	**0.000**
CESD Total	0.001	0.000	**0.000**	**0.000**	0.001	0.000	**0.000**	0.000	**0.000**	**0.000**	**0.000**
SWLS Total		0.035		**0.001**	0.070				**0.001**	**0.001**	**0.000**

*Only values significant at 0.05 level are presented, those with significance after Bonferroni adjustment (set at 0.05/11 tests $p < 0.0045$) (shown in bold).
CES-D: Centre for Epidemiologic Studies Depression; CIQ: Community Integration Measure; CIQ: Community Integration Questionnaire; COGLOG: Cognitive Log; CSI: Caregiver Strain Index; GOS-E: Glasgow Glasgow Outcome Scale-Extended; FIM-FAM: Functional Assessment Measure; SRB: Caregiver Self-Reported Burden; SWLS: Satisfaction With Life Scale.

significant differences in all scale scores across different GOS-E categories, which showed worse outcomes for those in the "severe disability" categories. There were no significant differences in scale scores across different event-related variables (Table IV).

DISCUSSION

TBI is a significant health problem in Australia. There are minimal data on longer term outcomes, particularly in participatory domains in *non-compensable* patients with TBI in the Australian community. This study examined factors associated with residual disability and restriction in participation over a longer term (up to 5 years post-injury) in a group of severely impaired trauma patients in the public healthcare system (previous studies have been in private compensable patient cohorts). This study therefore provides novel information and highlighted a number of key issues associated with these injuries that persist over a longer period. Consistent with other studies, participants in this study made a good functional recovery after treatment (high FIM-FAM motor scale scores); they reported residual neurological deficits, relationship and communication issues, the need for supervision or assistance in activities of daily living, and the presence of cognitive, behavioural, and emotional changes (17–19). Similar to other reports, the most common persistent neurological impairments included: pain (47%), headache (47%), followed by dizziness (36%), paresis (31%) and falls (31%). Over one-third reported bowel/bladder issues and sensory-perceptual deficits.

Of particular significance, this study used a set of validated measures to assess various injury-related outcomes. Although a majority of participants reported minimal change in their physical function and general cognitive abilities, they highlighted difficulties with daily activities and high levels of depression. The findings also suggest that, although most participants were well adjusted to community living, TBI has a negative impact on participants' social roles and community integration, and it jeopardizes their productivity, for example in studying or finding work. Factors significantly associated with a poorer current level of functioning and well-being in participants included: older age (≥ 60 years), the ongoing presence of TBI-related impairments, a lack of previous rehabilitation and those classified in the "severe disability" categories at admission. Several studies have reported the impact of age on post-injury outcomes, indicating worse functional outcomes and cognitive impairments in older age patients (> 50 years) at injury compared with their younger counterparts (17, 18, 37, 38).

Almost two-thirds of participants in this study had a formal caregiver. Of this group, more than half the caregivers reported high levels of strain for items such as the person with TBI displaying upsetting behaviours; and emotional and family adjustments due to disrupted routine. The caregiving burden was higher in those caring for the more severely affected persons with TBI, especially those with higher depression, anxiety and stress levels. Similarly increased behavioural problems between 1 and 5 years after injury was reported earlier in a follow-up study (based on relatives' accounts) (39). This highlights the need for interventions to reduce caregiver strain and burden in those at risk to reduce poor outcomes among both caregivers and care recipients with TBI.

This study has some potential limitations. Firstly, the data were collected through a cross-sectional survey and do not provide longitudinal information. Secondly, the study cohort is a non-compensable cohort listed on a database held at single public tertiary institution (RMH), which may limit the generalizability and validity of these findings. The study cohort, however, covers a wide geographical population in Victoria and represents the wider TBI population in the community. This study was intended as a preliminary descriptive study, with the aim of examining current clinical status of the TBI patient discharged into the community and identifying possible factors that may impact on long-term outcomes, including information from the perspective of the TBI participants in the community, and their caregivers. All questions were limited in the main to the current situation, in an attempt to reduce recall bias. Although validated measures assessed most outcomes, problems/issues not included within the domains of the outcome measures used were not able to be identified, such as substance abuse, common in TBI populations. We acknowledge that various other factors, which may have impacted on psychological outcomes in participants with TBI, such as participant insight into difficulties post-injury, were not fully explored. Patients with the worse outcomes may have had greater difficulties responding to participate in this study and there is the possibility of bias; however, it was not possible to follow the study non-responders. The measures used, nevertheless, were broad and expansive. More research into ongoing pain, seizures and cognitive outcomes is needed.

Understanding the impact of TBI in the longer term (beyond the acute phase) is important, as improved patient survival has shifted long-term patient management to ambulatory and community settings (2, 40). The challenge is that long-term physical and psychological morbidity associated with TBI can be under-estimated in these patient cohorts (2, 17, 40). Participation issues are taking on a greater significance in rehabilitation programmes as they are linked with long-term costs, impact on society and quality of life for the person with TBI and his/her family. The factors associated with long-term functional and psychological sequelae in participants with TBI have important implications for the treating clinicians. These highlight the need for a greater focus on TBI survivors' cognitive, psychological, and social problems that restrict their community participation. It is envisaged that the findings of this study will assist in the service planning and delivery and related health policy for sustainable rehabilitation models to improve long-terms outcome within the community for non-compensable patients with TBI in Victoria. Furthermore, it provides opportunities for knowledge transfer amongst clinicians, health administrators and policy developers; contributes to future research (benchmarking with national and international data) and benefits the community generally. Programmes providing a continuum of care from injury through to community integration have challenges that relate to the measurement of function appropriate to the phase of recovery and the measures being insensitive to functional changes over extended periods. Further research is needed using

larger multi-centre samples to understand the extent and issues of ageing and disability in these survivors.

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