MONASH University

Project Output Report

Monash-Epworth Rehabilitation Research Centre

Longitudinal Head Injury Outcome Project

January 2015 – June 2016

Jennie Ponsford and Gershon Spitz

18th August 2016

Research report #: 150-0816-R03

Acknowledgements

This research report was prepared by Jennie Ponsford and Gershon Spitz, Monash Epworth Rehabilitation Research Centre and Monash University, for the Transport Accident Commission Steering Committee.

We acknowledge the significant work contribution of all MERRC staff members involved in the conceptualisation and design of individual studies, collection of data, and manuscript preparation.

This project is funded by WorkSafe Victoria and the Transport Accident Commission, through the Institute for Safety, Compensation and Recovery Research.

ISCRR is a joint initiative of WorkSafe Victoria, the Transport Accident Commission and Monash University.

Contents

Manuscripts relevant to this report

	Reference	Status	Date
1.	Spitz, G., Hassani-Mahmooei, B., McKenzie, D., Ponsford, J. *Predicting return to work following traumatic brain injury using measures of service utilization.* Paper to be submitted August 2016.	To be Submitted	August 2016
2.	Ponsford J, Spitz G. *Classifying traumatic brain injury in the post-acute period: associations with background, injury-related, and outcome factors*.	Internal report	July2016
3.	Ponsford, J., Downing, M., Pechlivanidis, H. *The impact of cultural background on outcome following traumatic brain injury*. To be submitted August 2016.	To be Submitted	August 2016
4.	Downing, M., Ponsford, J. *Sexuality in individuals with traumatic brain injury and their partners*. Revised and resubmitted to Neuropsychological Rehabilitation, July 2016.	Re-submitted	July 2016
5.	Spitz G, Alway Y, Gould K, Ponsford J. Disrupted white matter connectivity and mood disorders following traumatic brain injury. Paper submitted to the Journal of Neurotrauma, Revised and resubmitted to Journal of Neurotrauma, July 2016.	Re-submitted	July 2016
6.	Alway, Y., Gould, K., McKay, A., Johnston, L., Ponsford, J. *The evolution of post-traumatic stress disorder following moderate-to-severe traumatic brain injury*. Journal of Neurotrauma, 2016, 33: 825-831.	Published	May 2016
7.	Ponsford, J., Spitz, G., & McKenzie, D. *Using post-traumatic amnesia to predict outcome following traumatic brain injury*. Journal of Neurotrauma. 2016, 33: 997-1004.	Published	May 2016
8.	Love, J., McKay, A., & Ponsford, J. *Agitation during post-traumatic amnesia*. Paper submitted to the Journal of Head Trauma Rehabilitation, April 2016.	Submitted	April 2016
9.	Roberts, C. M., Spitz, G., & Ponsford, J. L. *Comparing Prospectively Recorded Posttraumatic Amnesia Duration With Retrospective Accounts*. Journal of Head Trauma Rehabilitation. 2016, 31: E71-E77	Published	March 2016
10.	Alway, Y., Gould, K., Johnston, L., McKenzie, D., Ponsford, J. (2016). *A prospective examination of Axis I psychiatric disorders in the first 5 years following moderate to severe traumatic brain injury*. Psychological Medicine. 2016, 41: 1331-1341.	Published	February 2016
11.	Stolwyk, R., & Ponsford, J. *Reporting of neuropsychological dysfunction remains discrepant between individuals with traumatic brain injury and their close others up to five years post-injury*. Disability and Rehabilitation, 2016, 38: 1463-1470.	Published	December 2015
12.	Alway, Y., McKay, A., Gould, K., Johnston, L., Ponsford, J. *Factors associated with posttraumatic stress disorder following moderate to severe traumatic brain injury: A prospective study*. Depression and Anxiety. 2015: 33, 19-26.	Published	July 2015
13.	Roberts, C. M., Spitz, G., & Ponsford, J. L. *Retrospective analysis of the recovery of orientation and memory during posttraumatic amnesia*. Neuropsychology, 2015, 29,:522-529	Published	July 2015
14.	Spitz, G., McKenzie, D., Attwood, D., & Ponsford, J. L. (2015). *Cost prediction following traumatic brain injury: model development and validation*. Journal of Neurology, Neurosurgery & Psychiatry, 2016, 87: 173-180.	Published	February 2015

Presentations relevant to this report

	Reference	Type	Date
1.	Ponsford, J., Downing, M., Pechlivanidis, H. *The influence of cultural factors on outcome following traumatic brain injury.* Platform Paper, 13th Conference of the NeuroRehabilitation Special Interest Group of the World Federation of NeuroRehabilitation,(NR-SIG-WFNR), Glasgow, 11-12 July, 2016.	Oral presentation	July 2016
2.	Ponsford, J. *Traumatic brain injury: How can we improve outcome*. Invited lecture, School of Psychological Science, University of Maastricht, The Netherlands, 7 March, 2016.	Invited lecture	March 2016
3.	Ponsford, J., Gould, K., Alway, Y., Spitz. *Psychiatric disorders following traumatic brain injury: Their nature and treatment*. Invited workshop, 11th World Congress on Brain Injury, The Hague, Netherlands, 2-5 March 2016.	Invited conference workshop	March 2016
4.	Ponsford, J. Lee, N., Wong, D., McKay, A., Haines, K., Downing, M., Alway, Y., Furtado, C. O'Donnell, M. *Efficacy of motivational interviewing and cognitive behaviour therapy for anxiety and depression following traumatic brain injury.* Platform Paper, Invited workshop on Psychiatric disorders following traumatic brain injury at the 11th World Congress on Brain Injury, The Hague, Netherlands, 2-5 March 2016.	Oral presentation	March 2016
5.	Ponsford, J. *Traumatic brain injury: The challenge to improve outcome*. Workshop, Center for Brain Injury Rehabilitation, Copenhagen, Denmark, 9 March 2016.	Invited conference workshop	March 2016
6.	Ponsford, J. *Sexuality following brain injury – A much ignored problem.* Keynote address, Annual Conference of the British Psychological Society Division of Neuropsychology, London, UK 27 November, 2015.	Conference keynote address	November 2015
7.	Ponsford, J. *Traumatic brain injury.* Invited lecture, Department of Psychology, University of Oslo, 15 September, 2015.	Invited lecture	September 2015
8.	Ponsford, J. *Traumatic brain injury: How can we improve outcome?* Invited lecture, Institute of Cognitive Neuroscience, Trinity College, Dublin, 28 September, 2015.	Invited lecture	September 2015
9.	Ponsford, J. *Traumatic brain injury: The Challenge to Improve Outcome.* Invited Keynote Address, 5th Conference of the European Societies of Neuropsychology, 9-11 September, 2015, Tampere Finland.	Conference keynote address	September 2015
10.	McKay, A., Love, J., Ponsford, J. *Agitation during post-traumatic amnesia and its association with disorientation and impairments of memory*. Platform Paper, 12th Conference of the Neuropsychological Rehabilitation Special Interest group of the World Federation of NeuroRehabilitation, Daydream Island, 6-7 July, 2015.	Oral presentation	July 2015
11.	Ponsford, J., Spitz, G., McKenzie, D. *Using posttraumatic amnesia to predict outcome following traumatic brain injury.* Platform Paper, 12th Conference of the Neuropsychological Rehabilitation Special Interest group of the World Federation of NeuroRehabilitation, Daydream Island, 6-7 July, 2015.	Oral presentation	July 2015
12.	Ponsford, J. *Psychological Therapy for Anxiety and Depression following Traumatic Brain Injury.* Platform Paper, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Oral presentation	July 2015
13.	Spitz, G., McKenzie, D., Attwood, D., Ponsford, J. *Predicting cost following traumatic brain injury.* Platform Paper, 5th INS/ASSBI Pacific	Oral presentation	July 2015

	Rim Conference, Sydney, 1-4 July 2015. **Awarded the INS Nelson Butters prize for the best paper by a postgraduate researcher:**		
14.	McKay, A., Love, J., Ponsford, J. *Agitation during post-traumatic amnesia and its association with disorientation and impairments of memory*. Platform Paper, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Oral presentation	July 2015
15.	Alway, Y., Gould, K., Johnston, L., Ponsford, J. *Psychiatric Disorders in the first 5-years following Traumatic Brain Injury*. Platform Paper, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015. **Awarded an INS SLC special award for best student abstract.**	Oral presentation	July 2015
16.	Willmott, C., Spitz, G., Ponsford, J. *Predicting educational and vocational outcomes in adolescents and young adults studying prior to injury*. Platform Paper, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Oral presentation	July 2015
17.	Stolwyk, R. Charlton, J., Gooden, J., Ponsford, J. *Characterising the profile of on-road driving behaviour following traumatic brain injury.* Platform Paper, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Oral presentation	July 2015
18.	McKay, A., Ross, P., Ponsford, J. *Predictors of driving behaviour after TBI: Comparing cognitive tests, injury factors, and demographics.* Platform Paper, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Oral presentation	July 2015
19.	Pais, C, Gould, K., Wong, D., Ponsford, J. *Factors Associated with Post-traumatic Growth Following Traumatic Brain Injury.* Poster, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Poster	July 2015
20.	Withiel, T. Ponsford, J., Willmott, C. *Cognitive and Functional Outcomes after Traumatic Brain Injury: An investigation of COMT Val158Met.* Poster, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Poster	July 2015
21.	Bryce, S. Spitz, G., Ponsford, J. *Examining the validity of the AUDIT and DAST in screening for substance use disorders following TBI.* Poster, 5th INS/ASSBI Pacific Rim Conference, Sydney, 1-4 July 2015.	Poster	July 2015
22.	Ponsford, J. *The nature, trajectory and treatment of psychiatric disorders following traumatic brain injury.* Invited keynote lecture, Annual conference of the North American Brain Injury Society, San Antonio, Texas, 29 April-2 May, 2015.	Conference keynote address	May 2015
23.	Ponsford J. *TBI outcome.* Invited lecture, NABIS Legal Conference, San Antonio, Texas, 30 April-1 May 2015.	Invited lecture	May 2015
24.	Ponsford, J. *Achieving community reintegration and return to employment and study after traumatic brain Injury.* Invited Lecture, Graduate School of Comprehensive Human Sciences, University of Tsukuba, Tokyo, Japan, 30 March, 2015.	Invited lecture	March 2015
25.	Ponsford, J. *Working with families.* Invited lecture, NeuroRehabilitation Medicine and Innovation Conference, Singapore, 28 March, 2015.	Invited lecture	March 2015
26.	Ponsford, J. *Community reintegration following traumatic brain injury. What are the challenges?* Invited Keynote Address, Singapore Rehabilitation Conference, Singapore, 26-27 March, 2015.	Conference keynote address	March 2015
27.	Ponsford, J. *Goal management in traumatic brain injury.* Invited lecture, Singapore Rehabilitation Conference, Singapore, 26-27 March, 2015.	Invited lecture	March 2015
28.	Ponsford, J. Spitz, G., Downing,M., McKenzie, D. *Mortality following*	Conference	February 2015

	traumatic brain injury and rehabilitation. Poster, 43rd Annual meeting of the International Neuropsychological Society, Denver, USA, February 4-7, 2015.	poster	
29.	Ponsford, J. *Achieving meaningful outcomes following traumatic brain injury: A rehabilitationist's perspective.* Opening Keynote Address, Brain Injury Summit, Vail, Colorado, USA, 11-13 January, 2015	Conference keynote address	January 2015
30.	Ponsford, J. *Psychological therapy for anxiety and depression following traumatic brain injury.* Invited keynote address, Brain Injury Summit, Vail, Colorado, USA, 11-13 January, 2015.	Conference keynote address	January 2015
31.	Ponsford, J. *Sexuality following traumatic brain injury.* Invited keynote address, Brain Injury Summit, Vail, Colorado, USA, 11-13 January, 2015.	Conference keynote address	January 2015

1. Executive Summary

1.1 Purpose

The Longitudinal Head Injury Outcome Study follows up a large cohort of individuals who have sustained moderate to severe Traumatic Brain Injury (TBI). This project aims to provide a comprehensive picture of the changes experienced by people who have sustained a TBI as well as their families over a period of 20 years. Changes are captured in terms of living skills, study, employment, recreation, as well as social and personal relationships. In addition, factors predicting outcomes are identified in each of these domains. Over time, this study will elucidate the evolution of changes across the lifespan of the individual and their resultant impact on independence and occupational, social and emotional aspects of everyday living.

The overarching purpose of the study is to improve functional outcomes and quality of life as well as reduce cost in relation to individuals with TBI serviced by the TAC. This includes identifying the needs of TAC clients at various times across their lifespan, which will assist the TAC to most efficiently and effectively plan how to meet the long-term needs of their clients. This will ensure clients with TBI are supported in order to achieve the highest possible level of independence and participation in work, study, community, and family life. This documentation presents published manuscripts and reports for the period January 2015–June 2016 that have stemmed from the Monash-Epworth Rehabilitation Research Centre Longitudinal Head Injury Outcome Project.

1.2 Rationale

The project, underpinned by the substantial and longstanding database, is one of the most comprehensive worldwide and provides the TAC with access to a significant body of research that directly impacts client outcomes. This provides an evidence base to support TAC operational and strategic objectives, including cost-prediction and service utilisation. The number of publications and international conference presentations emanating from the research gives the TAC a significant international profile. These studies have continued to provide the underpinnings for interventions that aim to improve long-term outcomes and thus reduce long-term care and allied-health costs.

1.3 Methods

The Monash-Epworth Rehabilitation Research Centre Longitudinal Head Injury Outcome Project prospectively interviews individuals with complicated mild-to-severe traumatic brain injury (TBI) up to 20 years following their injury. They are interviewed at 1, 2, 3, 5, 10, and 20 years following injury. We have now interviewed a total of more than 2600 patients, 1610 at 1 year, 1543 at 2 years, 1123 at 3 years, 1069 at 5 years 470 at 10 years and 156 at 20 years post-injury. Patients complete a Structured Outcome Questionnaire, assessing neurological functioning, mobility, cognition, communication, emotional state, independence in activities of daily living, leisure activities,

employment, and relationship status. Other questionnaires completed include the Extended Glasgow Outcome Scale, Sickness Impact Profile, Craig Handicap Assessment and Reporting Technique, and Hospital Anxiety and Depression Scale. In addition, families complete the Family Assessment Device.

Specific studies have also been conducted. With a view to better understanding factors associated with good and poor outcomes, we have examined clinically meaningful outcome groups that differ in regards to cognition, personal strengths, environmental support, and performance validity. Using the Compensation Research Database, we have extracted costs for hospital, medical, paramedical/allied-health and long-term care costs for the first 10 years following injury. We have also leveraged the Compensation Research Database to extract longitudinal income benefit payments. This has allowed us to examine, in a larger cohort and in a more fine-grained manner, the patterns or profiles of return to work over the first three years following injury. We have continued to study the evolution and causes of psychiatric disorders, by administering the Structured Clinical Interview for DSM-IV at 3, 6 and 12 months post-injury and annually thereafter up to five years post-injury. We have continued our in-depth study of people from culturally and linguistically diverse backgrounds. In addition, families and partners have been enrolled in our research studies and we have captured ratings of sexual functioning from partners as well as individuals with TBI.

1.4 Research findings and implications

The Monash-Epworth Rehabilitation Research Centre has continued to leverage the Longitudinal Head Injury Outcome study database, and more recently the Compensation research database, to identify and examine areas of importance. Through our newly developed collaboration with TIRR Memorial Hermann in the USA, we have been able to group individuals based on their profile of symptoms. We have highlighted the presence of a good recovery group as well as groups of individuals who show poorer outcomes despite having similar injury severity. These are associated with greater emotional distress, low economic and family support, low resilience and greater service utilisation. This group also incurs greater costs. We also identified a group of individuals who were potentially affected by reduced self-awareness of injury-related changes, leading to under-reporting of problems and conversely by emotional distress potentially leading to some over-reporting of symptoms. Our findings further highlighted the factors other than injury severity that contribute to longer-term outcomes. These include the personal strengths of the individual, including independence and self-esteem and resilience, as well as economic and family supports, their level of emotional distress and motivation to recover. Having identified these key measures and profiles in patients assessed 6 months-10 years post-injury we now aim to see if these measures are predictive in the early stages after injury. If it is possible to identify these groups early we may be able to develop and tailor appropriate treatments to address issues relevant to each profile with the ultimate aim of improving outcomes.

We have identified some key predictors of early return to work (RTW) as well as more persistent unemployment. Individuals were more likely to return to work in the first 6 months if they had shorter duration of post traumatic amnesia (PTA) and if they were in managerial or professional occupations prior to injury. A combination of background, injury-related, and service utilisation variables predicted more persistent unemployment between 6 months and three years post-injury. Individuals were more likely to experience a protracted RTW if they were older, female, were labourers, machinery workers, or technician prior to injury, had longer duration of PTA, and had a moderate or major limb injury. In addition, greater utilisation of specialist practitioner, psychology services, and analgesic medication within the first 6 months was associated with delayed RTW. Conversely, assessment and rehabilitation for return to driving was associated with earlier RTW, highlighting the importance of driving for RTW. These findings demonstrate the roles of complex physical injuries, pain and mental health factors in delaying return to employment following TBI. A proactive approach to addressing these impediments in the return to work process is warranted and requires evaluation.

A significant proportion of costs following TBI could be predicted using background and injury-related factors that were readily available at or soon after the injury. Nearly half of hospital costs and one third of long-term care costs were predicted, while the models predicting medical and paramedical costs accounted for around a quarter of cost variability. Duration of post-traumatic amnesia was the single best predictor for each cost type. PTA duration was also a stronger predictor of costs than Glasgow Coma Score. PTA was the sole predictor of long term care costs, explaining 34% of the variability. Presence of other injuries also contributed significantly to cost prediction across all cost subtypes. Limb and chest injuries predicted 26% of medical costs. Greater hospital costs were predicted by more severe injuries (assessed using PTA and GCS), presence of a limb injury, older age at injury, and not being married or de facto prior to injury. Greater medical costs were predicted by longer duration of PTA, and the presence of limb and chest injuries. Greater paramedical costs were predicted by longer duration of PTA and living in metropolitan areas. Excessive or problem drinking was associated with lower paramedical costs.

As discussed above, PTA is one of the strongest predictors of outcome following TBI. Therefore, accurate determination of PTA duration has implications for the timing and focus of treatment and rehabilitation, as well as prediction of outcomes to provide prognostic information to families, determine future needs and resources required and inform legal proceedings. Our results highlighted that greater standardisation is required in the measurement of PTA, with prospective measurement on a daily basis being optimal. We found that retrospectively assessing duration of PTA resulted in both under- and over-estimation of true PTA duration.

The Psychiatric Study is the world's first prospective study of the evolution of the full range of Axis I psychiatric disorders over the first five years after TBI. The cohort reached the 5-year post-injury

time-point in the last year, enabling the 5-year follow-up study to be completed. Results highlighted the high prevalence of psychiatric disturbance after TBI, particularly anxiety and depression, which often occur comorbidly and evolve gradually over the first year post-injury. Substance use, which is a prominent psychiatric disorder pre-injury, tends to decline after TBI. Although having a pre-injury psychiatric disorder is strongly associated with having a post-injury psychiatric disorder, many individuals develop novel disorders. Anxiety disorders peak at one year and decline thereafter. Depressive disorders are more persistent. Individuals with limb injuries, who are particularly vulnerable to psychiatric disorders, may require additional support to manage pain and adjust to the impact of their injury on independence, work and leisure activities. Given the negative impact of anxiety and depression on functional outcomes, development and evaluation of interventions to prevent or alleviate anxiety and depression is a priority. Hence we have evaluated in an NHMRC-funded randomised controlled trial, the impact of a manualised psychological therapy to reduce anxiety and depression following TBI and found this to reduce anxiety and depression symptoms.

Post-traumatic stress disorder was the most common anxiety disorder and was associated with poor quality of life. PTSD was most commonly diagnosed between 6 and 12 months post-injury. Extended periods of PTA, cognitive dysfunction and hospitalisation following TBI may postpone symptom development rather than reduce the risk, with subsyndromal symptoms frequently preceding the development of full PTSD. This provides a potential time-window for early identification and treatment. Rehabilitation clinicians should be aware that patients might develop clinically significant trauma symptoms despite protracted post-traumatic amnesia. There was high comorbidity between PTSD, anxiety, and depression as well. It is important to identify and adapt treatment for overlapping mood, anxiety, and trauma symptoms.

Our cross-cultural study has demonstrated the strong influence of cultural background on outcome following TBI over and above injury severity and other demographic factors. As a group, individuals from culturally and linguistically diverse (CALD) backgrounds reported less independence in daily activities, were more emotionally distressed, showed a heightened awareness of injury-related changes and less problem-focused coping than individuals from English-speaking backgrounds. They tended to believe that more external factors such as Chinese medicine, praying or having family take care of them would help their recovery. They were less likely to believe that their own behaviour could help their recovery. They were more distressed about role changes. However, there were marked differences across geocultural regions, and differences in the demographic characteristics of these subgroups (e.g., age, education) also appear to have been influential. The CALD group had similar injury severity and received a similar amount of paramedical/allied-health treatment. Although no generalisation can be made, clinicians need to be sensitive to these differing attitudes to injury and recovery and wherever possible encourage more problem-focused coping towards becoming more functionally independent in injured individuals and their families to achieve the best possible outcome.

More than half of our cohort of individuals with TBI has reported changes to their sexual functioning, which likely also influenced their partners. This prompted us to examine sexuality from the perspective of partners. Our findings suggested that a significant proportion of individuals have organically-based changes in sexual function as a consequence of TBI which reduce their capacity to have satisfactory sexual relationships. This, in turn, impacts on their partners. Far greater efforts are required to identify and address sexual dysfunction in individuals with TBI during rehabilitation and beyond and it is vital that their partners are actively included in this process. Providing information about possible problems is an important step. Possible medical causes need to be investigated and addressed, and counselling may assist with communication, relationship or emotional issues that could be contributing to difficulties.

1.5 Key translational messages

a) **The reliable prospective measurement of PTA as routine practice in all acute and rehabilitation hospitals is vital as a key predictor of prognosis and costs. There is a need to better understand PTA, including assessment of agitation and impact of ADL training in PTA.**

   <u>Action:</u> Epworth routinely administers the Westmead PTA scale and has encouraged reliable administration at the trauma centres. TAC could further facilitate this.

b) **Need greater consideration of pre-morbid factors as potential factors mediating response to injury, recovery, and mortality following TBI, including culture, nature of employment and psychiatric history, resilience and SES, as well as age, gender and education. Measuring these variables early after injury may help predict outcome and guide treatment.**

   <u>Action:</u> MERRC to collect measures early after injury to establish their predictive validity.

c) **There is a need for greater emphasis on cognitive and behavioural changes during the rehabilitation process. There is also a need for further investigations as to the most effective means of rehabilitating these functions.**

   <u>Action:</u> Jennie Ponsford was part of a group developing guidelines for cognitive rehabilitation published in the Journal of Head Trauma Rehabilitation in 2014, in collaboration with Drs Mark Bayley and Peter Bragge. She is currently leading a survey of current practice of rehabilitation clinicians in cognitive rehabilitation, with a view to identifying the gaps between guidelines and clinical practice.

d) **Need to develop effective means of rehabilitating fatigue and sleep following TBI.**

   <u>Action:</u> MERRC is currently conducting three randomised controlled trials of treatments for fatigue and sleep disturbances following TBI – namely trials of the

efficacy of light therapy for fatigue and sleepiness, efficacy of melatonin for sleep disturbance following TBI and efficacy of cognitive behavioural therapy for sleep disturbance and fatigue following TBI. Findings from these trials, if successful, will be broadly implemented.

e) Need for proactive support for workers/students in the process of return to employment/study.

Action: TAC needs to implement active OT vocational support for its TBI clients from the early stages after injury to maximise potential for return to employment. MERRC plans to develop a study investigating effective elements of support for return to work following TBI.

f) High rates of anxiety and depression necessitate early screening and evaluation of interventions to enhance mental health after TBI.

Action: MERRC recently completed a randomised controlled trial of cognitive behavioural therapy (CBT) for anxiety and depression following TBI, establishing the efficacy of a manualised adapted CBT intervention. We have run training workshops and are providing supervision to clinicians to provide this therapy. We are also conducting further analysis of the study tapes to identify the effective elements of the therapy.

g) Need to provide support for families to increase their capacity to provide a positive environment for the person with TBI.

Action: We evaluated in a waitlist controlled trial a Multi-Family Group intervention for families and individuals with severe TBI and demonstrated that it is effective in improving family functioning and social connectedness.

h) Addressing sexuality and relationships in the rehabilitation process.

Action: We aim to implement the routine provision of information on sexuality to individuals and their partners during the rehabilitation process.

2. Identifying different patterns of outcome and their predictors

Relevant citations:

Ponsford JL, Spitz G. *MERRC-TAC Linkage Report: Classification system for traumatic brain injury*. Internal report. 2016.

Sherer M., Nick TG., Sander AM., Melguizo M., Hanks R., Novack TA., Tulsky D., Kisala P., Luo C., Tang X. *Groupings of persons with traumatic brain injury: a new approach to classifying traumatic brain injury in the post-acute period*. Journal of Head Trauma Rehabilitation. 2016,

2.1 Background

The Monash-Epworth Rehabilitation Research Centre (MERRC) is currently participating in an international collaboration with the aim of identifying clusters of individuals with traumatic brain injury according to their outcomes. In an initial study using a large cohort of TBI participants in the USA, Sherer et al. (2015) identified five groups of individuals who differed on 12 dimensions assessing cognitive, personal strengths, environmental, and performance validity factors. Following from this, MERRC conducted interviews with individuals from the longitudinal outcome study using these same 12 dimensions in order to examine whether this five-group solution could be applied to Australian individuals with TBI. A recent report has subsequently confirmed that the five-group solution can also be applied in the Australian cohort. This report confirmed the presence of five clinically meaningful groups in the Australian TBI sample (refer to Figure 1):

- Group 1 is characterised by average cognitive functioning relative to the group but reported few problems across all self-report measures. That is, they denied cognitive, post-concussional or physical symptoms, showed high independence, self-esteem and resilience, low emotional distress and had good economic and family support, while showing symptom validity.
- Group 2 is characterised by significantly greater cognitive difficulties, but showed only moderate reporting of cognitive, post-concussional and physical symptoms, reported intermediate levels of independence, self-esteem and resilience, emotional distress, physical functioning and economic and family support. They displayed adequate symptom validity.
- Group 3 displayed the most intact cognitive functioning, performing the best of all groups on cognitive measures. They reported slightly above average physical functioning, but showed intermediate reporting of cognitive, post-concussional and physical symptoms, and reported intermediate levels of independence, self-esteem, resilience and emotional distress, as well as adequate symptom validity.
- Group 4 displayed intermediate levels of cognitive functioning relative to the rest of the group, but reported the highest levels of cognitive, post-concussional and physical symptoms, lowest independence, self-esteem and resilience, highest emotional distress, lowest physical function

and low levels of economic and family support. They, nevertheless, displayed intact symptom validity.

- Group 5 displayed poorer cognitive performance and reported high levels of cognitive, post-concussional and physical symptoms, low independence, self-esteem and resilience, high emotional distress, low physical functioning and lower than average economic and family support. This group showed low symptom validity.

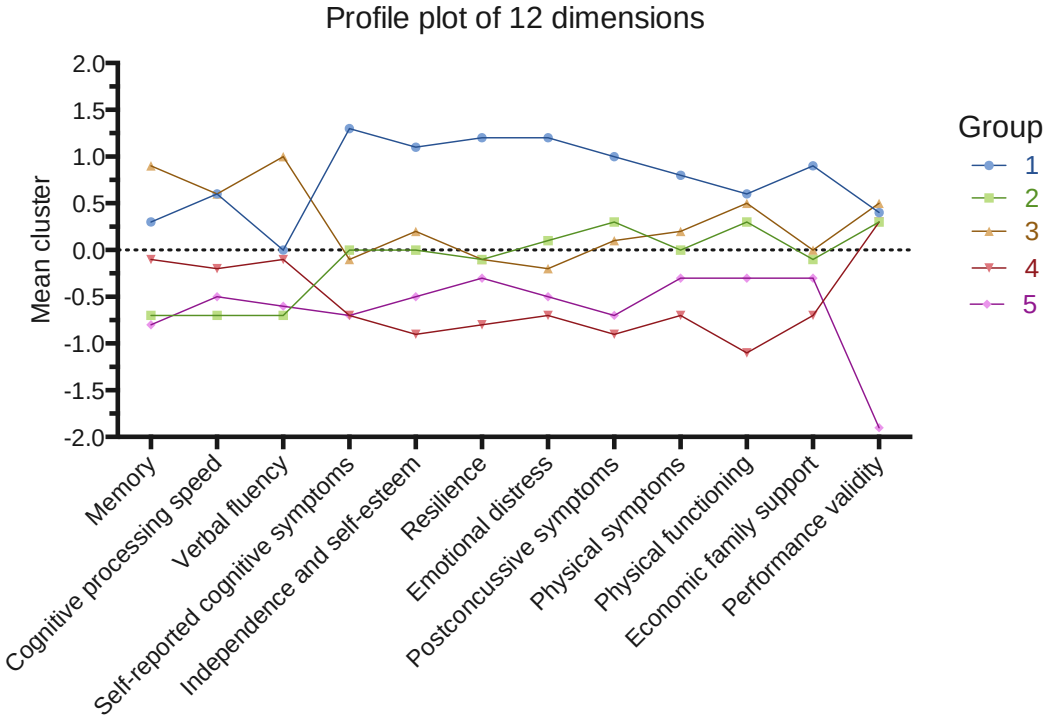

Figure 1. Dimension score for the five groups

Although the Australian TBI cohort can be clustered into five clinically meaningful profiles we do not yet know whether these groups differ on meaningful outcomes, such as community participation. In addition, there is no evidence that these five groups differ in regards to their TAC claim profiles. Demonstrating differences between the groups in recovery outcomes and service utilisation will provide further evidence and justification for these groupings. It would further highlight the potential for different treatment options depending on the individual's profile in regards to the 12 dimensions.

2.2 Objectives

a) To examine whether the five groups differed on background and injury-related factors.

b) To examine differences between groups on community participation outcomes.

c) To examine whether groups differed in accrued costs for long-term care, medical, and allied health services.

2.3 Key Findings

- Several significant relationships were found between group membership and background, community participation, and service utilisation.
- The five groups did not differ significantly in severity of injury, as assessed using both the duration of post-traumatic amnesia (PTA) and Glasgow Coma Score (GCS). This indicates that differences between community participation and service utilisation are more likely attributable, at least in part, to factors other than injury severity.
- Group 1 displayed the best community participation outcomes, whereas group 4 and 5 showed the poorest outcomes. This aligns with the group scores on the 12 dimensions.
- Group 1 likely comprises good copers. Although displaying intermediate cognitive deficits, they reported few problems across all self-report measures. They denied cognitive, post-concussional or physical symptoms, showed high independence, self-esteem and resilience, low emotional distress and had good economic and family support, while showing good symptom validity.
- Groups 4 and 5 reported the highest levels of cognitive, post-concussional and physical symptoms, lowest independence, self-esteem and resilience, highest emotional distress, lowest physical function and low levels of economic and family support.
- Group 4 reported symptoms despite performing at an intermediate level on cognitive measures. They showed adequate performance validity. Thus their self-report appears to be influenced by emotional distress.
- Group 5 performed more poorly on cognitive measures but also presented with poor performance validity, indicating potential lack of effort or other patterns of reporting not aligned with their neurological symptoms.
- Compared to group 1, groups 4 and 5 displayed poorer productivity, social outcomes, as well as overall community participation, probably reflecting increased emotional distress and in the case of group 5 low motivation to recover.
- Group 1 displayed the least accrued costs and frequency of service utilisation. Conversely, groups 4 and 5 accrued greater overall costs and service utilisation. Groups 4 and 5 more frequently used long-term care, general, and specialist practitioner services. In addition, groups 4 and 5 more frequently used analgesic, antidepressant, neuropathic pain, and schedule 8 medications, again reflecting higher levels of emotional distress, pain and in the case of group 5 possibly low motivation to recover.
- Group 2 displayed severe cognitive impairments but despite these reported only intermediate levels of symptoms, physical functioning and emotional distress. This group may lack self-awareness of their limitations.

- Groups 3, conversely, showed good cognitive performances and no physical limitations, but self-reported intermediate levels of symptoms and emotional distress. They appear to be more distressed by their symptoms.

2.4 Clinical implications and translational opportunities

- These findings highlight the presence of a good recovery group, group 1, as well as groups of individuals, namely those in groups 4 and 5, who are characterised by poorer outcomes associated with greater emotional distress, low economic and family support, low resilience and greater service utilisation.
- Other groups, whilst not differing significantly on participation outcomes, were potentially affected by reduced self-awareness of injury-related changes, leading to under-reporting of problems (group 2) and conversely by emotional distress potentially leading to some over-reporting of symptoms (group 3).
- Because these groups did not differ on initial severity of injury these results confirm that factors other than injury severity contribute to longer term outcomes. These include the personal strengths of the individual, including independence and self-esteem and resilience, as well as economic and family supports, their level of emotional distress and motivation to recover.
- This study is allowing us to identify and measure some of the factors, other than injury severity, that contribute to poorer long-term levels of participation and greater costs to the TAC. These factors relate to personal resilience, and psychological responses to injury and pain, the latter being associated with poorer outcomes.
- Conversely, personal resilience, self-esteem, education, and economic and social supports are significant protective factors, being associated with good outcomes even in the face of persistent cognitive impairments.

2.5 Future directions

- The next step in this research will be for us to gather these measures early after injury and examine whether they can be used early after injury to predict these various trajectories.
- The ultimate aim of this study will be to provide the TAC and the community of clinicians with an algorithm for identifying the likely trajectory of a given patient and an associated projected cost estimate. A further aim will be to develop and trial different treatment approaches adapted to the needs of each subgroup.

3. Return to work following traumatic brain injury

Relevant citations:
Spitz, G., Hassani-Mahmooei, B., McKenzie, D., Ponsford, J. *Predicting return to work following traumatic brain injury using measures of service utilization*. To be submitted, July 2016.

3.1 Background

Improving return to work (RTW) for severely injured clients is a specific priority area for the TAC. There is a need to develop models that capture the process of RTW for these clients. Such models could inform the TAC's provision of services to optimise return to employment. One way of improving client management is to develop profiles that predict earlier, as well as successful, RTW. By leveraging the Compensation Research Database (CRD) managed by the Transport Accident Commission and the Institute for Safety, Compensation, and Recovery Research (ISCRR) we were able to examine RTW in fine-grained analyses that have not previously been undertaken. In the current study we were able to detail RTW, using loss of earnings payment data obtained at monthly intervals over the first three years following TBI. This study comprised 666 individuals from the MERRC database who had been competitively employed prior to injury, for whom CRD data were available and who had received loss of earnings payments after injury. In addition, using the CRD we were able to begin examining whether specific types of service utilisation were associated with employment status. Each individual's services were aggregated over the first six months post-injury. This included medical services, such as surgeries, pathology, radiology, and psychiatry, as well as allied health services, which included psychology, social work, and vocational assistance.

3.2 Objectives

a) To examine whether background and injury-related variables can explain early return to work, within the first six months.

b) To examine whether the type of service utilisation can assist in predicting persistent unemployment, beyond six months following injury.

3.3 Key Findings

- 16% of individuals competitively employed prior to injury returned to work within the first six months following their injury.
- The majority of individuals experienced more persistent unemployment. Even at three years, 50% of individuals in competitive employment prior to injury had not yet returned to work.
- Return to work within the first six months was more likely for those who were more highly educated, had a higher relative socio-economic advantage, were in managerial or professional occupations prior to their injury, and had milder injuries—assessed using duration of PTA.
- Labourers, machinery workers, or technicians as well as individuals sustaining a moderate or major limb injury were significantly less likely to experience early return to work.

- When combining these factors within a multivariate model, managerial/professional occupations prior to injury and lower severity of injury best explained early return to work.
- Likelihood of returning to work at a later stage, beyond six months post-injury, unlike early return to work, was associated with both gender and age. Duration of unemployment was greater for females and older individuals.
- Type of premorbid occupation was also related to later return to work. However, whereas managers and professionals were more likely to return to work earlier, being a labourer, machinists, or technician was associated with more prolonged unemployment. Reasons why managers and professionals are more likely to return to employment early require further exploration. Early return to work for managers and professionals might be related to motivational factors, to greater loyalty or flexibility on the part of employers or to the fact that these occupations often do not require physical exertion. However the cognitive difficulties and mental fatigue that are so common would be likely to disrupt return to work for these individuals. Conversely, it may be that labourers, machinery workers and technicians have lower motivation to RTW, are more hampered by physical injuries and fatigue and/or have less sympathetic employers.
- Longer PTA as well as moderate or major limb injuries was also associated with prolonged unemployment.
- Using a greater number of specialist practitioner and psychological services, as well as analgesic medication was associated with more prolonged unemployment. This highlights the roles of complex physical injuries, pain and mental health factors in delaying return to employment following TBI.
- Receiving driving assessment and rehabilitation was related to a greater likelihood of returning to work. These processes are closely linked because capacity to drive is an important factor in fitness for work.
- Use of Epworth OT and external RTW services were associated with a greater likelihood of returning to work. The aim of these services is to plan a RTW program with the patient and employer in accordance with the requirements of the occupation. These services also provide ongoing support and adjustment as required. The current findings suggest providing these services is a key factor in facilitating return to work. Therefore ensuring TAC clients receive such services if they have potential to return to employment is imperative.
- These findings are consistent with an earlier analysis performed examining stability of employment over the first three years post-TBI, which also identified injury severity, nature of pre-injury employment and mobility as significant predictive factors (Ponsford and Spitz, 2014).

3.4 Clinical implications and translational opportunities

- This study has highlighted some key predictors of early RTW, namely shorter PTA duration and being in a managerial or professional occupation.
- Impediments to RTW were also highlighted, namely being female, older, being a labourer, machinery worker or technician, having longer PTA or having a moderate or major limb injury.
- This knowledge can be used to inform the provision of vocational services. It may also be that vocational support services can be fast-tracked for certain individuals likely to RTW early, but that special attention might also be paid to those groups at risk of delayed RTW,
- Vocational services need to be made available to those not returning to work over extended periods. Given the significance of pre-injury employment type, it is important that vocational counsellors or treating occupational therapists have early and frequent liaison with all employers to maximise their continuing engagement with the client during the recovery process and willingness to modify duties as necessary. This contact should continue after the person has returned to work to trouble-shoot any problems.
- Where return to work is delayed by protracted recovery from limb injuries or more severe head injury, vocational providers need to remain engaged with injured clients and their employers. Negotiating options for modified duties or hours may facilitate RTW.
- Where the person cannot return to their previous job, aggressive attempts need to be made to facilitate exploration of alternative options and support, as well as provide the necessary training over long periods of time post-injury.
- Timely management of pain and psychological impediments to RTW is extremely important.
- Special attention should be paid to ensuring that females and those who are older receive every possible support to RTW.
- Driver assessment and rehabilitation represents an important component in the process of RTW. This therefore needs to happen in a systematic and timely fashion.

3.5 Future directions

- Future directions of the research will be to identify why various employee groups differ in time taken to RTW.
- To formally evaluate the impact of provision of intensive vocational support on outcomes.

4. Developing models of cost following traumatic brain injury

Relevant citations:

Spitz, G., McKenzie, D., Attwood, D., & Ponsford, J. L. (2015). *Cost prediction following traumatic brain injury: model development and validation.* *Journal of Neurology, Neurosurgery & Psychiatry*, jnnp-2014.

4.1 Background

The lifetime costs of each traumatic brain injury in Australia is estimated to be $A2.5 million for moderate and $A4.8 million for severe injuries. These include costs for hospital and medical care, allied health therapy, equipment and modifications, long term care, and loss of productivity. However, there is currently no clear basis on which to predict such costs for a given individual. Therefore, the current study developed predictive multivariate models of costs accrued from the time of injury and over the subsequent 10 years. Costs were predicted for hospital, medical, paramedical, and long-term care following complicated mild to severe TBI. The study sample comprised 798 participants who had reached 10 years post-injury, for whom costing data was available from the TAC and for whom complete data were available for chosen demographic and injury-related variables.

4.2 Objectives

a) To develop competing predictive multivariate models of costs accrued from the time of the initial accident and over the subsequent 10 years following injury.

4.3 Key Findings

- A significant proportion of costs following TBI could be predicted using factors that were readily available at or soon after the injury.
- Nearly half of hospital costs and one third of long-term care costs were predicted, while the models predicting medical and paramedical costs accounted for around a quarter of cost variability.
- Duration of post-traumatic amnesia was the single best predictor for each cost type.
- PTA duration was also a stronger predictor of costs compared to Glasgow Coma Score.
- PTA was the sole predictor of long term care costs, explaining 34% of the variability.
- Presence of other injuries also contributed significantly to cost prediction across all cost subtypes.
- Limb and chest injuries predicted 26% of medical costs.
- Greater hospital costs were predicted by more severe injuries (assessed using PTA and GCS), presence of a limb injury, older age at injury, and not being married or de facto prior to injury.

- Greater medical costs were predicted by longer duration of PTA, and the presence of limb and chest injuries.
- Greater paramedical costs were predicted by longer duration of PTA, living in metropolitan areas. Excessive or problem drinking was associated with lower paramedical costs.

4.4 Clinical implications and translational opportunities

- The findings support the need for greater consistency in measurement of PTA duration as a measure of injury severity in patients surviving past acute injury hospital discharge.
- These findings may be used for the planning and case management of individuals following TBI.

4.5 Future directions

- Further research is required to examine the contribution of other factors to costs of care following moderate to severe TBI.
- An algorithm predicting costs could be developed.

5. Measurement of post traumatic amnesia following traumatic brain injury

Relevant citations:

Roberts, C. M., Spitz, G., & Ponsford, J. L. Comparing Prospectively Recorded Posttraumatic Amnesia Duration With Retrospective Accounts. Journal of Head Trauma Rehabilitation. 2016, 31: E71-E77

Roberts, C. M., Spitz, G., & Ponsford, J. L. Retrospective analysis of the recovery of orientation and memory during posttraumatic amnesia. Neuropsychology, 2015, 29,:522-529

5.1 Background

One of the strongest predictors of TBI severity and outcome is the duration of post traumatic amnesia (PTA), a period extending from the moment of injury until the point when memories can be formed and retained from one day to the next. One method of ascertaining the duration of PTA is to ask the individual with TBI what is their first memory following the injury after they have regained full consciousness. However, the accuracy of this retrospective account is dependent on their recall, which could be confounded by sedation, stress, and other injuries. Methods of prospectively assessing PTA on a daily basis were developed in an attempt to overcome some of the issues associated with determining PTA duration retrospectively. However, retrospective accounts are still being used clinically to determine duration of PTA, despite potential limitations with this approach and it is not known to what extent retrospective and prospective accounts of PTA align with each other. Prospective methods comprise items that examine the resolution of orientation to person (name, address, date of birth), place (name of place), and time (time, day, date) as well as new memory formation. However, the recovery of different items on prospective PTA scales, relating to aspects of orientation and memory, also requires further investigation. This study included patients who were admitted to the head injury unit at Epworth Hospital and had their PTA duration assessed prospectively as inpatients. Contacting participants ascertained retrospective accounts over the phone and completing a semi-structured interview to determine the day post-injury that continuous memory returned.

5.2 Objectives

a) To examine the association between PTA duration measured prospectively using the Westmead PTA scale and retrospectively estimated PTA duration assessed using a semi-structured telephone interview.

b) To retrospectively examine the recovery of Westmead PTA scale items that measure orientation to person, place, and time, as well as items assessing formation of new memories.

5.3 Key Findings

- A significant positive correlation was found between prospectively-acquired and retrospectively-acquired duration of PTA.
- 41% of participants reported a first memory that was different from the return of continuous memory, verifying the importance of additional questioning.
- Retrospectively-acquired duration of PTA was found to be significantly longer than prospectively-acquired estimates.
- Retrospective accounts overestimated PTA duration in 58% of cases and underestimated PTA duration in 37% of cases.
- Participants' ages and severity of injury were not related to the discrepancy between retrospective and prospective account of PTA duration.
- There was evidence that items relating to memories established before the injury recovered in order of remoteness, compared to items requiring formation of new memories. For example, the item assessing date of birth recovered more quickly than the item assessing the current year.
- Conversely, recovery of items requiring the formation of new memories recovered in order of complexity and frequency of change. For example, name of the hospital recovered earlier than the item assessing the current day.
- Although significant trends were observed in the recovery of items across the whole sample, the order of recovery was highly variable between individuals.

5.4 Clinical implications and translational opportunities

- Accurate determination of PTA duration has implications for the timing and focus of treatment and rehabilitation resources, information for families about prognosis, and determination of long-term care needs e.g., in legal proceedings.
- Therefore use of the Westmead PTA scale administered prospectively on a daily basis in all settings providing management of acute TBI is important.
- Caution must be exercised during assessment of PTA, since a correct response on a single occasion does not guarantee that the item will be responded to correctly for the remainder of the testing period.
- A wide range of potential factors likely contributes to variations in the order of recovery of the Westmead PTA scale items. We need to consider differences in injury pathology, fluctuations in mood, behaviour, motivation, fatigue, and medical status on the day of assessment.

5.5 Future directions

- Future research should attempt to prospectively examine the concordance between prospective PTA duration and retrospective accounts of PTA duration within the same individual over time.
- Future research should also incorporate assessment of cognition, memory, and outcome at the time of retrospective interview, which would help determine the contribution of ongoing deficits in relation to the correspondence between prospective and retrospective assessments.

6. Psychiatric disorders in the first 5 years following TBI

Relevant citations:

Alway Y, Gould KR, Johnston L, McKenzie D, Ponsford J. *A prospective examination of Axis I psychiatric disorders in the first 5 years following moderate to severe traumatic brain injury.* Psychological Medicine 46, 1331-1341.

Ponsford J, Lee N, McKay A, Wong D, Haines K, Alway Y, Downing M, Furtado C, & O'Donnell M. (2015) *Efficacy of motivational interviewing and cognitive behavioural therapy for anxiety and depression symptoms following traumatic brain injury*. Psychological Medicine. Published Online Dec 2015; 1:1-12.

6.1 Background

Psychiatric disorders and traumatic brain injury (TBI) are leading causes of disability and burden. Psychiatric disorders exacerbate TBI-related disability and increase health expenditure and carer burden. Despite considerable research on psychiatric disorders following TBI, their timing of onset, course, and risk factors remain uncertain. There have been no prospective investigations examining a wide range of psychiatric disorders beyond the first year post-injury. An investigation of this is warranted to determine whether there are critical periods in the development and remission of post-injury disorders over longer time-frames. Participants were 161 individuals (78.3% male) with moderate (31.2%) or severe (68.8%) TBI. Psychiatric disorders were diagnosed using the Structured Clinical Interview for DSM-IV, administered soon after injury and 3, 6, and 12 months, 2, 3, 4, and 5 years post-injury. Disorder frequencies and generalised estimating equations were used to identify temporal relationships and risk factors.

6.2 Objectives

a) To investigate the frequency, patterns of comorbidity, and trajectory of Axis I psychiatric disorders in the first 5 years post-injury.

b) To examine whether disorder trajectories differ according to pre-injury psychiatric history status and other demographic and injury-related factors.

6.3 Key Findings

- The majority of participants (59%) had one or more Axis I disorder prior to injury, with rates and patterns equivalent to those in the Australian general population. Substance-use was the most common pre-injury diagnostic class, with approximately a third and a fifth meeting criteria for alcohol-use or drug-use disorder, respectively. One fifth had mood and anxiety disorders prior to injury.

- Findings confirmed the high frequency of psychiatric diagnoses during the first 5 years post-injury, with 75% receiving one or more psychiatric diagnoses, most commonly depressive and/or anxiety disorders, during the first 5 years, significantly higher than pre-injury rates.
- Males and females showed similar rates of psychiatric disorders.
- Comorbidity of disorders was common, with approximately half the sample having two or more diagnostic classes, often anxiety and depression.
- Over the five years, disorder frequency ranged between 35.6% and 61.8%. Disorder frequencies were higher than in the Australian general population up to the fourth year post-injury. However, rates of post-injury psychotic, eating, somatoform and adjustment disorders appeared comparable to prevalence estimates in the general population.
- Most cases emerged within the first year and there was a steady decline thereafter, with disorder likelihood decreasing by 27% with each year post-injury. Findings support the first year as being a high-risk period for the development of psychiatric disorders following TBI.
- Major depressive disorder was the most common mood disorder and post-traumatic stress disorder (PTSD) was the most common classifiable anxiety disorder.
- Relative to population rates, anxiety disorders were elevated only in the first year after injury, whilst rates of mood disorder remained at least four times greater up to 5 years post-injury.
- Post-injury mood disorders appear to be more chronic/recurrent in course than anxiety disorders. Rates of substance use disorder, which were high pre-injury, declined after injury.
- Two-thirds of cases developed a diagnosis not present prior to injury. Most commonly, individuals with substance use disorder developed anxiety and/or depressive disorders.
- A significant proportion without a psychiatric history also developed a disorder post-injury, often between six and 12 months after injury and 56.5% experienced a novel diagnostic class not present prior to injury.
- A pre-injury psychiatric disorder was the strongest predictor of post-injury disorder during the 5-year follow-up period.
- Accident-related limb injury was also a significant predictor of post-injury Axis I disorder.
- The likelihood of disorder increased with greater age up to 30 years and declined with greater age thereafter.
- Gender, education and PTA duration were not significantly associated with Axis I psychiatric disorder.
- In terms of treatment, participants with an Axis I psychiatric diagnosis had higher rates of mental health specific intervention than those without. Across follow-ups, around one-third with a diagnosis were prescribed psychotropic medication and approximately three-fifths counselling, whilst rates of psychiatric inpatient admission were low (mean = 3.2%).

6.4 Clinical implications and translational opportunities

- Psychiatric presentations following TBI do not merely represent a continuation of pre-injury disorders into the post-injury period. Although having a pre-injury psychiatric history is a major risk factor, the nature of the diagnosis may change after injury, most often from substance abuse to anxiety and/or depression. Many develop disorders for the first time.
- Individuals with limb injuries may require additional support to manage pain and adjust to the psychosocial impact of their injury, such as reduced independence and ability to return to occupational and leisure activities.
- The first year is the critical period in the emergence of psychiatric disorders following TBI. However, in many cases they do not emerge until 6-12 months post-injury. Therefore, early psychological or pharmacological interventions particularly targeting anxiety and depression symptoms have potential to minimise the development or severity of these disorders.
- The development and trialling of evidence-based psychological interventions that are adapted for individuals with cognitive impairments is desirable. With funding from NHMRC our research group has conducted a randomised controlled trial showing efficacy of adapted cognitive behavioural therapy (CBT) for anxiety and depression following TBI (Ponsford et al., 2015). We have found that those with and without pre-injury psychiatric symptoms are equally likely to respond to this therapy. The researchers are now evaluating the implementation of this manualised intervention, training clinicians in its use and evaluating the increase in their skill levels. This study is ongoing.
- In another study we are analysing the content of therapy to identify which therapy components and adaptations were used most frequently and the nature of therapeutic alliance and homework adherence and their impact on response to the intervention. This study will continue over the next two years.
- As part of a guidelines development study funded by ISCRR, Prof Jennie Ponsford together with Prof Malcolm Hopwood is conducting a series of systematic reviews towards development of NHMRC guidelines for pharmacological management of neurobehavioural disturbances after TBI that will include anxiety and depression.

6.5 Future directions

- This study represents the world's first prospective study examining the full range of Axis I psychiatric disorders over five years following TBI and has received worldwide attention.
- Given findings from retrospective studies indicating high rates of disorders for several decades, further follow-up is imperative to understand the long-term trajectory of psychiatry disorders following TBI. We plan to follow this cohort over 10 years post-injury.

- Understanding of the respective contributions of pre-injury characteristics, TBI-related neuropathology and post-injury adjustment concerns requires further investigation and this is continuing.
- There is a need to strengthen the evidence base for effective psychological and pharmacological treatment in TBI populations and we are continuing this as described above, by training clinicians to implement the manualised CBT intervention. In another study we have commenced analysing the content of adapted cognitive behavioural therapy to identify which therapy components and adaptations were used most frequently and the nature of therapeutic alliance and homework adherence and their impact on response to the intervention. This study will continue over the next two years.
- As part of a guidelines development study funded by ISCRR, Prof Jennie Ponsford together with Prof Malcolm Hopwood is conducting a series of systematic reviews towards development of NHMRC guidelines for pharmacological management of neurobehavioural disturbances after TBI, which will include anxiety and depression.

7. Post-traumatic stress disorder following traumatic brain injury

Relevant citations:

Alway Y, Gould KR, McKay A, Johnston L, Ponsford J. *The evolution of post-traumatic stress disorder following moderate-to-severe traumatic brain injury.* Journal of Neurotrauma 33, 825-831.

Alway Y, McKay A, Gould KR, Johnston L, Ponsford J. *Factors associated with posttraumatic stress disorder following moderate to severe traumatic brain injury: a prospective study.* Depression and Anxiety 33, 19-26.

7.1 Background

Traumatic brain injury involves the experience of a traumatic and potentially life-threatening event, including motor-vehicle accidents, falls, and assaults. The recovery process also involves confronting medical procedures, extended hospitalisation, and adjustment to physical and cognitive disability. Therefore, there is the potential for individuals to develop post-traumatic stress disorder (PTSD), characterised by debilitating trauma-specific re-experiencing symptoms, avoidance behaviours, and physiological hyperarousal. Understanding the frequency with which PTSD occurs following TBI is challenging due to the overlap in symptoms characteristic of both TBI and PTSD. These include changes in memory, concentration, and sleep disturbances. No previous study has used a diagnostic interview to prospectively examine the evolution of PTSD over several years following moderate-to-severe TBI. In addition, the factors associated with PTSD following moderate to severe TBI are not well established. Therefore, these studies also prospectively examined the preinjury, injury-related, and postinjury factors associated with PTSD over the first 5 years following TBI. Participants were individuals with moderate to severe TBI recruited following admission to acute rehabilitation between 2005 and 2010. Using the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (SCID-I), participants were evaluated for pre- and post-injury PTSD soon after injury and reassessed at 6 and 12 months, 2, 3, 4, and 5 years post-injury.

7.2 Objectives

a) To prospectively examine the evolution of PTSD over several years following moderate-to-severe TBI, examining the frequency, timing of onset, temporal trajectory, symptom profile, and rates of comorbid psychiatric disorders.

b) To examine pretrauma (i.e., female gender, younger age, fewer years of education, prior psychiatric disorder), peritrauma (i.e., accident/injury severity), and posttrauma (i.e., acute stress disorder) risk factors for PTSD following TBI.

c) To examine whether injury-related PTSD is associated with psychiatric comorbidity and poorer functional and quality of life outcomes following TBI.

7.3 Key Findings

- During the first 4 years following TBI, 18% of participants developed injury-related PTSD.
- The majority of injury-related PTSD cases had a delayed-onset, peaking between 6 and 12 months following injury.
- The majority of participants exhibited a chronic symptom course, which in some cases fluctuated between PTSD, subthreshold, and no PTSD over the 4-year period.
- Injury-related PTSD was not found to be more common in those with a pre-injury history of PTSD or another psychiatric disorder.
- Every participant with injury-related PTSD developed another post-injury psychiatric disorder, with mood and other anxiety disorder being the most common.
- Age, gender, and education were unrelated to injury-related PTSD.
- There was some evidence that greater TBI severity may reduce risk for PTSD. Although duration of post-traumatic amnesia did not differ between those with and without injury-related PTSD, when concurrent post-injury factors were controlled for, shorter PTA duration was associated with an elevated risk for PTSD.
- Lack of memory for the traumatic event does not preclude PTSD from developing following TBI.
- PTSD is associated with lower functional outcome and quality of life.

7.4 Clinical implications and translational opportunities

- The association between PTSD and lower quality of life following TBI highlights the need to direct clinical attention to the treatment of comorbid PTSD following TBI to improve outcomes of those affected.
- As PTSD symptoms typically emerge during the first year post-injury, early identification and treatment is critical. Subsyndromal symptoms frequently preceded the development of full PTSD. Clinicians need to be looking out for such symptoms. They warrant clinical attention as they may indicate emergent or fluctuating full PTSD.
- Given the high rates of comorbidity in this sample, it is important to identify and adapt treatment for overlapping mood, anxiety, and trauma symptoms.

7.5 Future directions

- Further research is required to examine the long-term trajectory of PTSD symptoms to understand whether delayed-onset cases continue to emerge over time, and whether such typical chronic presentations eventually resolve. This study is continuing up to10 years post-injury.
- Further research is needed investigating pre-, peri-, and post-trauma risk factors for PTSD, including factors such as social support and post-injury stressful life events.

- Individuals with PTSD have been treated within the randomised controlled trial of motivational interviewing and cognitive behavioural therapy for anxiety and depression following TBI. Further examination of the ways in which they responded to this intervention will shed light on effective treatments in this population.

8. Influence of cultural diversity on outcome following traumatic brain injury

Relevant citations:

Ponsford J, Downing M, Pechlivanidis H. *The impact of cultural background on outcomes following traumatic brain injury.* Submitted to…

8.1 Background

A range of demographic, injury-related, and post-injury factors influences outcome following TBI. Increasingly, it has also become apparent that race and ethnicity also influences outcome following TBI. The present study examined whether race/ethnicity influenced rehabilitation outcomes in the Australian rehabilitation context. 104 individuals with TBI from English-speaking background (ESB) and 99 individuals from culturally and linguistically diverse (CALD) backgrounds (43 different NESB countries) were assessed an average 22.3 months post-injury with the following measures: Brief Acculturation Scale, Craig Handicap Assessment and Reporting Technique, Activities of Daily Living independence, Coping Scale for Adults, and the Hospital Anxiety and Depression Scale.

8.2 Objectives

a) To examine patterns of outcome following TBI in individuals from an English-Speaking Background (ESB) compared to those from Culturally and Linguistically Diverse (CALD) backgrounds.

8.3 Key Findings

- There were no significant differences between the two groups on demographic and injury-related variables. However, CALD participants showed lower pre-injury employment rates.
- There were no significant differences between ESB and CALD groups in regards to allied therapy costs although there was a trend for CALD participants to have lower costs.
- At post-injury follow-up, individuals in the CALD group were significantly less independent than the ESB group in light domestic duties, shopping and financial management.
- The CALD groups also reported significantly lower cognitive independence, mobility and participation in occupational and social activities.
- There was no difference between ESB and CALD groups in regards to rates of return to study or employment following their injury, with CALD employment rates remaining proportionately lower.
- CALD participants reported significantly heightened awareness of post-injury deficits relative to ESB participants.
- The groups held different beliefs regarding factors that would aid their recovery. CALD participants were less likely to believe changing their health habits or being a better person

would help their recovery. They were more likely to believe that having family take care of them, Chinese medicine, and praying/confession would aid in their recovery.

- The CALD group also reported significantly more anxiety symptoms and reported significantly lower levels of problem-focused coping.
- However, there were marked differences across geocultural regions, and differences in the demographic characteristics of these subgroups (e.g., age, education) also appear to have been influential.

8.4 Clinical implications and translational opportunities

- These findings highlight the need to consider individual cultures as well as the demographic factors that may be interacting with outcomes and response to injury.
- There is a need to train clinicians to be aware of the impact of cultural beliefs on response to injury and recovery so they can be incorporated into the rehabilitation process. There may be a need for more intensive support after return to the community to ensure that independence levels are maximised and that families provide support in the most constructive fashion. More problem-focused coping should be encouraged. It is possible that some individuals from CALD backgrounds do not access paramedical services over the longer term as much as others. The challenge will be to see whether outcomes can be improved by changing practices.

8.5 Future directions

- To examine the trajectory of change over time to identify more specifically when and where differences appear between ESB and CALD groups, and what are the contributing factors.
- To continue to increase the sample size within specific cultural groups to allow for statistical comparison across geocultural groups.

9. Changes in sexuality following traumatic brain injury

Relevant citations:

Downing M, Ponsford J. *Sexuality in individuals with traumatic brain injury and their partners*. Submitted to Neuropsychological Rehabilitation.

9.1 Background

Changes in cognitive, physical, social and behavioural domains can have a significant influence on individuals and their partners. Following TBI, individuals report changes in sexuality and sexual behaviour, which may subsequently influence individual's partners. Although previous studies by MERRC and others have detailed the impact of TBI on the injured individual's sexuality, few studies have investigated couples' sexuality where one partner has sustained a TBI. Fifty-six individuals who had sustained TBI and their partners completed the Derogatis Interview for Sexual Function–Self Report (DISF-SR). Results were compared with normative data.

9.2 Objectives

a) To identify changes or issues in sexual function in individuals who had sustained TBI and their partners.

9.3 Key Findings

- Individuals with TBI tended to score lower than their partners on the measure of sexual functioning
- The partners' T-scores were generally below average. Although the scores for the TBI individual were on average lower than those of their partners across all subscales, the only statistically significant difference between TBI participants and their partners was found on the orgasm subscale.
- Approximately one third of the TBI group scored below the 2nd percentile for orgasm, as well as for sexual arousal, sex drive, and overall sexual function score.
- Participants with TBI were more likely to have lower interest in sex compared to their partners, which included both men and women.

9.4 Clinical implications and translational opportunities

- The findings suggest that a significant proportion of individuals with TBI have organically based changes in sexual function as a consequence of TBI.
- These impact on their sexuality and that of their partners.
- There may also be relationship issues that contribute to a decline in sexual functioning, including cognitive and behavioural changes as well as other stressors.

- Far greater efforts are required to identify and address sexual dysfunction in individuals with TBI during rehabilitation and beyond. It is vital that their partners are actively included in this process.
- Providing information about possible problems is an important step and psychotherapy and counselling may assist with communication, relationship or emotional issues that could be contributing to difficulties.

9.5 Future directions

- There is a need to implement regular provision of information about injury related sexual changes to individuals with TBI and their partners, and provide access to medical and psychological investigations and supports to alleviate changes experienced.