

## SUMMARY OF RESEARCH FINDINGS

*This research summary provides an overview of a research project completed through the Institute for Safety, Compensation and Recovery Research (ISCRR). For more information, visit the ISCRR website at [www.iscrr.com.au](http://www.iscrr.com.au)*

Following a traumatic brain injury, the injured person can experience chronic and distressing changes in behaviour such as aggression, agitation, sexual inappropriateness and lack of interest in activities the person used to enjoy. These behaviours, termed 'behaviours of concern' can create significant challenges for the injured person, their family or their carer. The causes of these behaviours and their management are often complex.

### WHAT WAS DONE IN THIS PROJECT?

This research project comprised two studies aimed at enhancing the understanding of behaviours of concern in TAC clients with traumatic brain injury.

The first study was a retrospective analysis of TAC clients with traumatic brain injury who had recorded incidences of behaviours of concern post injury. A total of 65 injured clients and 62 family members or carers of these clients were surveyed. Participants completed a structured interview and behaviours of concern were documented by the family member/carer using the Overt Behaviour Scale, a tool for measuring the severity, frequency and impact of common behaviours of concern.

The second study explored the lived experience of behaviours of concern following traumatic brain injury and included both TAC clients and non-compensable individuals (i.e. individuals injured by assault or in a fall, or without access to statutory compensation in Victoria). Interviews were conducted with the person with traumatic brain injury, a family member/carer and a clinician involved in their care. Individuals with traumatic brain injury and associated behaviours of concern were recruited from two sources: six were TAC clients recruited from the first study and five were non-compensable participants recruited from a community brain disorders service. In total, 25 semi-structured qualitative interviews were conducted (nine with injured individuals, nine with family members/carers and seven with clinicians).

### WHAT WAS FOUND?

The findings from study one provided insight into the types, severity, impact and recognition of behaviours of concern.

#### Behaviour types and severity:

- 71% of participants had exhibited one or more behaviour of concern over the previous three months and a quarter had the highest level of severity for the three most common behaviours (verbal aggression, inappropriate social behaviour and lack of initiation).
- Most individuals described increases in anger, frustration and irritability as well as mood swings post injury. Approximately 39% were receiving professional support (such as psychology or neuropsychology) for this behaviour, and most were highly satisfied with this, although others identified a need for further support.
- 81% of participants reported that their behaviour had changed since the injury and 82.4% stated that this change was ongoing.

A joint initiative of

### **Impact of behaviours:**

- The behaviour which had the greatest impact on the participant's family member/carer was severe verbal aggression (such as threats of violence or suicide).

### **Recognition of behaviours:**

- Comparisons between the reports of individuals with traumatic brain injury and their family member/carer highlighted poor agreement regarding behaviour change post injury. While most injured individuals reported some behaviour change post injury, their family member/carer was still more likely to report that the individual's behaviour had changed post injury.
- This study was one of the first to examine behaviour change from the perspective of the individual with traumatic brain injury, with most identifying that anger or mood swings that they experienced post injury were still impacting their lives on average 11 years later.

### **Themes emerging from interviews:**

In study two, frequent and persistent behaviours of concern were reported in the interviews. Participants identified the following factors as central to life after injury and spoke about the relationship between these concerns and behaviour:

- issues related to the brain injury (e.g. the impact of memory problems)
- loss of control (e.g. feeling that they had little control over what happened to them day to day)
- accommodation type (e.g. participants living in the community reported that behaviours of concern were closely related to self-identity and social relationships, whereas those living in supervised residential care reported that behaviours of concern often related to their environment and their attempts to control it)
- the importance of routine and consistency in their lives
- mood (e.g. depression, anxiety, anger and post-traumatic stress)
- identity (e.g. comparing themselves with pre-injury)
- social relationships (e.g. losing friendships due to their behaviours)
- meaningful participation (e.g. the absence of purposeful activities or access to education and employment).

## **WHAT ARE THE IMPLICATIONS OF THE RESEARCH?**

The findings of both studies highlight the need for long-term behaviour support for individuals with traumatic brain injury. They also highlight the benefit of including the perspective of the individual with the injury, as well as their family member/carer to further our understanding of the nature, frequency and factors relating to behaviours of concern after traumatic brain injury.

The themes emerging from the study can be used to inform future interventions designed to reduce behaviours of concern by targeting the specific challenges identified by the injured individuals, their family members/carers and clinicians. Together, the findings suggest a need to provide long-term professional support and a positive environment in which individuals with traumatic brain injury feel they have a greater sense of control.

The next phase of this research involves evaluating the effectiveness of a promising evidence-based model for addressing behaviours of concern – the Positive Behaviour Support model.

## **PROJECT OVERVIEW**

**Project title** Understanding behaviours of concern (ISCR Project 084)

**Themes** Traumatic brain injury, behaviours of concern, residential care, positive behaviour support interventions

**Researchers** Jennie Ponsford, Malcolm Hopwood, Justin Kenardy, Kate Rachel Gould, Amelia J Hicks, Iveta Krivos

**Relevant outputs** Reducing behaviours of concern following traumatic brain injury - phase 1