The Pathways of Young People with Acquired Brain Injury at Risk of Placement in Residential Aged Care.

September 2014
Executive Summary

Purpose

This study provides an overview of findings from the first 18 months of the Pathways Project (December 2012-June 2014). This research was provided in-kind by the Summer Foundation to ISCRR's ABI Rehabilitation Research Program.

Rationale

Past research by the Summer Foundation and Monash University demonstrates that young people who live in residential aged care most often are admitted directly from a hospital setting (Winkler, Holgate, Sloan & Callaway, 2012; Winkler et al, 2007). The range of housing and support models available, particularly when the person is not deemed "ready" for traditional inpatient rehabilitation, are limited to return home with family support; being wait-listed for a placement in disability-specific shared supported accommodation; or entering aged care (Callaway, Winkler, Sloan et al, 2013). The restricted options available leads to extended length of stay, hospital bed-blocking and, often, ultimately transfer of the young person to residential aged care.

This study aims to document the pathways of young adults with severe ABI who experience prolonged acute hospital stay over their first 24-months post-injury from the acute setting to their residence post-rehabilitation vai a case study series.

This study examines consecutive admission to a major acute health and trauma centre in Melbourne, Victoria during 2012-13 (baseline data); acute and sub-acute rehabilitation and community settings (longitudinal data).

Fourteen people aged between 16-65 years who sustained a traumatic or non-traumatic severe ABI (Glasgow Coma Scale score $\leqslant$11 or post-traumatic amnesia $\geqslant$7 days, and Care and Needs Scale rating of Level 7), were admitted to the specified setting post injury, and had stayed $\geqslant$14 days in that setting. Participant response rate to date ~ 88%

Methods

This is an ongoing prospective study, with recruitment at $\geqslant$14 days post injury and longitudinal data collection scheduled at five time points – baseline ($\geqslant$14 days post-injury, with pre-injury data gathered simultaneously), 3 months, 6 months, 12 months, 18 months and 24 months post injury. Measures include: the Glasgow Outcome Scale-Extended, SF-12, EQ-5D, Health of a Nation Outcomes Scale–ABI, Care and Needs Scale, Functional Independence Measure, Community Integration Questionnaire, Sydney Psychosocial Reintegration Scale, and Role Checklist. In addition, two measures of family outcome were used with a nominated family member: Preparedness for Caregiving Scale (at discharge) and the Family Outcome Measure (at 6, 12, 18, and 24 month time points).

Interim Research Findings & Implications

Participants' average age at the time of ABI was 36 years (SD=15 years, R=17-61 years); nine (64%) were male. Ten participants sustained traumatic brain injuries and four experienced

cerebrovascular accident. Two passed away during the course of the study; one received palliation care and passed away four months post-ABI, while the other passed away unexpectedly from a subsequent cerebrovascular accident 53 days post-injury. Nine were eligible for compensation for their injuries through the Transport Accident Commission, including one of the participants who passed away.

It was found the level of support required by participants at baseline (⩾14 days post-ABI) was very high for all (as expected given study inclusion criteria), but varied by 12 months post-injury. However, support needs remained near 24-hour care for six of the eight participants who have 12 month data collected. Three participants returned to the acute setting on several occasions each through the early days of their rehabilitation. As of the most recent interviews completed in this reporting period, two people had been discharged to residential aged care, five people returned home with support, five people continued inpatient rehabilitation and two people have passed away.

The researchers also found community integration outcomes post-ABI varied but participants still displayed significant deficits for most at 12-18 months post-ABI, especially in productivity and home integration activities. These participation deficits are also evident in the number life roles with which participants identified compared to pre-ABI, underscoring the significant reduction in social connectedness and participation that is experienced by people with severe ABI.

A comprehensive recruitment strategy was used in this study. Nevertheless, smaller than anticipated participant numbers have been seen. Following an initial 10 months of the project, inclusion criteria for length of stay was reduced from 30 days to 14 days in order to attempt to recruit eligible participants prior to their transfer from the recruitment setting. The adjustment was based on emerging clinical evidence that length of stay and the pathways to discharge from the acute setting have changed over time**.**

Where once individuals who sustained severe to catastrophic brain injury remained in the acute setting of a major hospital for ~30 days, this project identified evidence of people being transferred back to original treating hospitals as soon as emergency medical intervention was provided, or discharged to the rehabilitation setting earlier than has been previously seen. This finding, coupled with a reduction in the incidence of road-accident related traumatic injuries in the preceding year, appear to have affected recruitment.

Implications of the research

- Notwithstanding the small participant numbers, the interim results in this study begin to highlight the complex and enduring support needs of participants and their impact on length of acute hospital stay, access to rehabilitation, and long term outcomes following ABI.
- The study begins to draws attention to the restricted range of housing and support options available to this target group, which post-rehabilitation most often consist of return home with high levels of paid or family support, or discharge to residential aged care.
- There is a need for significant systemic change to offer access to slow stream rehabilitation and a range of community-based support models to improve long term outcomes and reduce cost of care of this complex group. In Victoria, the Caulfield ABI rehabilitation service may begin to address this systemic issue.
- For those not in receipt of compensation, discharge planning may be enhanced by access to timely support and equipment which may be offered through a National Disability Insurance Scheme, once launched nationally.

Authors
Callaway L. [1,2]
Migliorini, C.. [1,2]

[1] Monash University, [2] Summer Foundation,

Where can I get further information?
For copies of the full report please contact:

Institute for Safety, Compensation and Recovery Research
Phone: +613 9097 0610, Email: info@iscrr.com.au

Accompanying documents to this report

This project is ongoing and does not have a final reseach report yet.