Transition outcomes for women with TBI

Title: Sentinel events during the transition from hospital to home: a longitudinal study of women with a traumatic brain injury

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Sentinel events during the transition from hospital to home: a longitudinal study of women with a traumatic brain injury

Abstract:

Objective: To describe the occurrence of sentinel events and their influence on community integration of women with a traumatic brain injury (TBI) transitioning from hospital to home.

Design: A longitudinal study was completed with data collected prior to, and at 1, 3 and 6-months following, hospital discharge. **Setting:** Participants were recruited from a brain injury rehabilitation unit and an acute neurosciences ward. **Participants:** The sample included 25 women, aged between 17 and 50, with severe TBI (duration of post traumatic amnesia ranged from 1-123 days). Sixteen family caregivers also participated. **Interventions:** Not applicable.

Main outcome measures: Community integration was measured using the Mayo-Portland Adaptability Inventory (MPAI). Depression, anxiety and stress were measured using the Depression Anxiety Stress Scale (DASS). The Sentinel Events Questionnaire (SEQ) was used to record life events that potentially influence the transition process. **Results:** The majority of women (over 16 at each time-point) experienced mild-moderate impairments in psychosocial integration. A third of the sample reported symptoms of depression (n=8), anxiety (n=9), and stress (n=7) that exceeded clinical cut-off levels on at least one occasion. At 6-months three women reported clinically significant depression and anxiety (12%), and two reported significant stress levels (8%). Positive sentinel events such as return to meaningful occupation were common (n=14). Negative events were also quite common. For example, reduced access to therapy, reported by 10 women, was associated with poorer participation levels. **Conclusion:** These findings suggest that the presence of sentinel events influences the transition experiences

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of women with TBI in this sample. Rehabilitation should consider the occurrence and impact of sentinel events as this may facilitate successful transitions.

Key words: rehabilitation, participation, traumatic brain injury, gender

List of abbreviations:

TBI Traumatic brain injury p.3

ABI Acquired brain injury p.4

MPAI Mayo Portland Adaptability Inventory p.7

DASS Depression Anxiety Stress Scale p.8

SEQ Sentinel events questionnaire p.8

PTA Post traumatic amnesia p.9

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Transition from hospital to home is recognised as a critical phase of healthcare delivery¹ and, among survivors of traumatic brain injury (TBI), represents a time of enormous adjustment during which they and their family members develop greater awareness of changes in their roles, relationships and abilities.² Understanding what occurs during this time is fundamental to ensuring optimal community integration,^{3,4} yet there is a dearth of research addressing this time period for individuals with TBI. This study focuses on describing transition outcomes for women with TBI.

Transitioning from a patient at a hospital to a person living in their own home involves a change in, and/or resumption of pre-injury roles and responsibilities and the process is influenced by life events.^{5,6} Investigating the life events that occur during transition from hospital to home for survivors of TBI may provide contextual information that explains outcomes including community integration.² It may also suggest avenues for rehabilitation that will ultimately improve community integration outcomes. To date, longitudinal studies following individuals with TBI have focused on measuring outcomes at specific points in time (typically from at least 1 year post-injury), but have not described the life events affecting the transition process.

It is well known that during the first six months following TBI, individuals with moderate to severe TBI have lower levels of productivity as well as lower levels of home and social integration.⁷⁻⁹ While some improvements have been observed in community integration over longer time periods, average scores remained lower than those measured pre-injury.⁷ Other studies have noted additional challenges associated with the transition from hospital to home. For

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example, one study found that individuals with acquired brain injury (ABI) report higher levels of depression and stress at 3-months post discharge compared to during hospitalization.⁸ Whilst these investigations provide important information on outcomes following discharge from hospital, they do not describe sentinel events, that is, events other than discharge itself that may influence the level of community integration occurring in the transition period.

In our previous work examining sentinel events in the context of transition,^{10, 11} we defined these as either positive or negative events that arise in the life course of individuals with TBI.^{10, 12} Based on our pilot work,¹¹ we identified critical events to be included in a sentinel events questionnaire: positive sentinel events such as returning to meaningful occupation, resumption of independence in the home, return to independent use of transportation and driving, and negative sentinel events of financial strain (e.g., borrowing money, loss of employment income, accessing welfare or savings plans), relationship breakdown, accommodation change, and difficulty accessing therapy services.^{10, 12} However, one limitation of this work is that we did not investigate how sex and/or gender influences the occurrence and lived experiences of these events.

Though women represent one-third of all individuals with TBI, there is a paucity of evidence characterising their transition process from hospital to home. Links between sex, gender and health are well established in the literature.¹³ In one study, women at least 5 years post-TBI were more likely to report poor overall health, problems with emotional wellbeing, fatigue, and reproductive problems, than were their healthy counterparts.¹⁴ Differential patterns in symptom

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severity have also been noted. For example, males have been reported to have greater impairments in executive functioning and memory^{15, 16} whereas females report higher levels of fatigue, anxiety, and depression.^{17, 18} It is therefore reasonable to hypothesise that women may have unique experiences when transitioning to the home from the hospital and that these should be identified and addressed, in order to provide optimal rehabilitation. It is also important to examine how sex and gender influence outcomes for family caregivers. Disrupted family functioning has been shown to have a greater negative impact on male caregivers¹⁹ and gender of the TBI survivor (i.e., female) has been linked to poorer family system functioning.²⁰

In this study we undertook an analysis of the occurrence of sentinel events during transition from hospital to home and the influence of these events upon transition outcomes among a sample of women with TBI. Our primary purpose in this research was to generate hypotheses regarding the experiences of transition for women with TBI, which would lead to future investigations of sex and gender differences needing consideration during rehabilitation, and during the transition period. Specific research questions were: (a) what is the pattern of occurrence of sentinel events during the transition from hospital to home for women with TBI, (b) what are the outcomes for women with TBI and their family caregivers during the transition from hospital to home, and (c) is there a connection between the occurrence of sentinel events and community integration? No specific hypotheses were formulated given the exploratory nature of this study.

Methods:

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Design:

Data for this hypothesis generating study were collected as part of a larger prospective longitudinal cohort study investigating the transition from hospital to home.¹⁰ The transition phase is hereafter defined as extending from hospital discharge to 6-months following community re-entry. Quantitative data were collected in the week leading up to discharge, which became the baseline measure, and then at 1, 3 and 6-months following discharge. Relevant hospital and university ethics committees approved this study.

Sample:

Data from a sample of 25 women with TBI who had participated in a larger earlier study were examined. Participants in the larger study¹⁰ were recruited consecutively and prospectively at the time of discharge from an acute neurosciences ward (providing acute stroke, neurosurgery and neurology services) and an in-patient rehabilitation unit. Inclusion criteria were: moderate or severe TBI, working age (18 and 60 years), living in a community setting (i.e., not discharged to a hospital or rehabilitation facility), and sufficient cognitive and communication skills to provide informed consent and participate in an interview. For this study we added the additional inclusion criteria of being female. Participants were excluded if they were in hospital for a period of less than four days (this time-frame reflected local hospital protocols for the assessment of post-traumatic amnesia), or if they had a mental health condition which impeded the provision of informed consent (e.g., schizophrenia). Each participant was asked to identify a caregiver to participate in the study. The selected caregiver was the person who associated with them the most on a daily basis.

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130 Measures:

131 The Mayo Portland Adaptability Inventory-4 (MPAI²¹) was designed to capture the range of
132 physical, cognitive, emotional, behavioural and social problems which can arise following
133 acquired brain injury. The measure has three subscales reflecting the International Classification
134 of Functioning²²: abilities (n= 12 items), adjustment (n=12 items) and participation (n=8 items).
135 Items are rated on 5-point scales where 0 indicates total independence and 4 indicates a severe
136 problem that interferes with activities more than 75% of the time. The MPAI has acceptable
137 psychometrics²¹ and allows for the conversion of raw scores into standardised *T*-scores.
138 Standardized scores from individuals with ABI and their caregivers are reported in this paper.

139

140 Levels of depression, anxiety and stress for women with TBI and their family caregivers were
141 measured with the 21-item short form of the Depression Anxiety Stress Scale (DASS).^{23, 24}
142 Participants rate the extent to which they have experienced symptoms of depression, anxiety or
143 stress (defined as increased tension²⁵) over the past week on a scale of 0 (none of the time) to 3
144 (most of the time). For each of the three subscales (depression, anxiety, stress), relevant item
145 scores are summed and then multiplied by two to get a total score comparable to the full 42-item
146 measure. Clinical cut-off scores are that a score greater than 9 indicates significant depression,
147 greater than 7 indicates significant anxiety and greater than 14 significant stress. Research shows
148 the DASS to have acceptable psychometric properties.^{26, 27}

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The process of transition was examined using the Sentinel Events Questionnaire (SEQ),¹² which asks about the occurrence of eight defined events and the date at which they transpired. Events include financial strain (borrowing money or sale of assets), relationship breakdown (relationship ending or loss of contact with a significant friend or family member), changing living situation (e.g., returning to live with parents), difficulty accessing therapy services (being unable to access or continue with therapy despite wishing to do so), return to meaningful occupation (including paid employment, student, volunteer roles, childcare and/or caregiving responsibilities and home-making), able to stay at home alone for four or more hours, return to independent use of transportation (public transport or taxis) and return to driving (medical clearance to resume driving). Individuals can report multiple instances of each event and the dates at which they occurred. The SEQ also provides space for individuals to record other events deemed to have affected their life and transition. However, these data were not analysed due to the large variability in the data set. The SEQ was developed specifically to document the transition period of an ABI population¹¹ and has been shown to have acceptable participant-proxy agreement for all items (>80%).¹²

Demographic details were also recorded. Variables included age, years of education, pre-injury occupational status (paid work, unpaid work or unemployed), relationship status, cause of injury, duration of post-traumatic amnesia (PTA; measured using the Westmead PTA Scale²⁸), length of hospital stay and relation to caregiver.

Procedure:

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Baseline assessments were completed in the hospital via interview with a member of the research team. Follow-up data collection occurred via telephone, in-person interview, or via returning written responses to questionnaires by email or post. In cases where questionnaires were returned via post or email, a trained research assistant checked responses and participants were contacted to clarify responses as required. Demographic details were obtained by reviewing medical charts and through participant interviews. Women with TBI completed the MPAI, DASS and SEQ, and caregivers rated their own wellbeing on the DASS and provided a proxy-rating of women with TBI's functioning on the MPAI.

Planned analyses:

“Descriptive statistics were used to analyse demographic variables and Cohen's d statistic (the standardised measure of the difference between two means) was used as an indicator of effect size.”

To address the first research question, related to the pattern of occurrence of sentinel events for women with TBI in transition, descriptive statistics were used including frequencies of occurrence and time until the event occurred.

To address the second research question, related to transition outcomes for women with TBI and their caregivers, descriptive statistics were computed for the MPAI and DASS. A paired t-test

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was used to compare self-ratings of the MPAI between individuals with TBI and their caregivers at each time-point.

To address the third research question, related to the influence of sentinel events on community integration, two linear mixed effect models were run. As the sample size precluded examination of all eight events, two were selected for analysis to provide an example of how data pertaining to these events could be analysed in future research. Having difficulty accessing therapy may facilitate community integration by providing a means of improving ability. Return to meaningful activity may influence community integration in several ways (e.g., by increasing social integration, financial independence, or self-efficacy). Both models used MPAI participation scores as the outcome variable and PTA as a covariate (to control for injury severity). Sentinel events were used as explanatory variables, coded according to whether (or not) they had been reported by participants on at least one occasion during the transition period. These analyses included data from each time-point grouped by participant. Though missing data were present at each assessment, data were not imputed or dropped because participants returned to complete subsequent assessments. All data analyses were completed using Stata 11.²⁹

Results:

Sample characteristics:

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During the recruitment period, 218 individuals with TBI met the inclusion criteria for the larger study, 36 of whom were women. 8 women declined to consent and 3 were lost to follow-up resulting in a final sample of 25 women with TBI. This sample was compared to all non-respondents on key demographic variables (age, gender and length of hospital stay; see table 1). There were no differences in the proportion of women who consented and refused participation ($\chi^2(2, n=36) = 1.03$, Phi-coefficient=0.04). In the entire sample there was a moderate effect of age such that individuals declining consent were younger than those lost to follow-up ($d = 0.58$) and those who consented ($d = 0.43$). When looking only at women with TBI, the three women lost to follow-up, were older ($d=0.39$) and had a longer hospital stay ($d=0.61$) than women who declined to consent, and those in the study. Demographic characteristics of the sample are shown in Table 2. Of the 16 caregivers identified by participants, nine were males.

[insert tables 1 & 2 about here]

Sentinel events in the transition experiences of women with TBI:

All sentinel events included in the SEQ were present in the transition period and are shown in table 3 ordered in terms of their frequency of identification. The most frequently identified event, that of *being able to stay alone at home*, occurred for almost all women (23/25, 92%) and early in the transition period (mean of 25.7 days post-discharge). *Returning to meaningful occupation*, reported by 14 women (56%), was recorded if work, home-maker and/or student roles were resumed in any capacity including full time and other graded return to activity. Of those women who reported returning to meaningful activity: 12 (80%) returned to paid work; 2

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(13%) resumed primary responsibility for home-making duties; and 1 (7%) returned to studying.

One woman who cited home-making as her primary role prior to her injury resumed home-making tasks and started a new paid job. The timing of sentinel events was extremely varied as all had large standard deviations. Changing living situation which showed the least variability ranged in timing from 1-63 days

[insert table 3 about here]

Transition outcomes for women with TBI and their caregivers:

Table 4 presents summary statistics for the MPAI and DASS for women with TBI and their caregivers. Average scores on the MPAI changed little over time (i.e., the mean total score for women was 39.9 at baseline and at 6-months). At all time-points, the highest scores were on the participation and adjustment subscales, indicating that women with TBI had greatest difficulties in these domains. At baseline, women with TBI had significantly lower scores than their caregivers on the MPAI ability ($p=0.02$) and adjustment subscales ($p=0.03$) which suggests that either individuals with TBI under-report, or that caregivers over-report, problems during hospitalisation. There were no significant differences between women with TBI and caregivers at each post-discharge time point.

For women with TBI, average scores on the depression and stress subscales appear to increase up-until 3-months post-discharge before levelling off, whereas the average anxiety score

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continued to gradually increase over the six-month period observed. Three months post-discharge was when the highest number of women reported symptoms of depression (n=6, 24%), anxiety (n=6, 24%), and stress (n=4, 16%) above a clinical cut-off. By 6-months these numbers had slightly reduced; three women reported clinically significant depression and anxiety (12%), and two reported clinically significant stress levels (8%). Among caregivers, average scores on all subscales decreased between discharge and 3-months, and then increased between 3 and 6-months (see table 2). At each time point, fewer than 2 caregivers (13%) reported clinically significant depression, only 1 reported clinically significant anxiety (6%), and fewer than 3 noted clinically significant stress symptoms (18%). Eight of 16 caregivers reported clinically significant symptoms of depression, anxiety and/or stress and four of these were male.

[insert table 4 about here]

Impact of sentinel events upon community integration:

Linear mixed effect models explored the association between occurrence of sentinel events and level of participation of women with TBI, controlling for injury severity (PTA duration). Experiencing difficulty accessing therapy services was associated with reduced levels of participation among women with TBI (coefficient = 13.9, $p < 0.01$) and had a stronger association than PTA duration (coefficient = 0.17, $p = 0.01$). Return to meaningful occupation was associated with higher levels of participation (coefficient = -9.6, $p = 0.02$) and also showed a stronger association than PTA duration (coefficient = 0.13, $p = 0.07$).

Discussion:

To the authors' knowledge this is the first study describing sentinel events and their relationship to outcomes for women with TBI during the transition from hospital to home. Participants were recruited consecutively and followed prospectively during the six-month transition period. All sentinel events as measured by the SEQ were present in the transition experiences of women with TBI. Indeed, some events such as financial strain and difficulty accessing therapy services occurred on multiple occasions to the same individual. Encouragingly, positive events such as being able to stay at home alone and return to independent use of transportation were common, reported by over 20 women (> 80% of the sample). Of particular importance, 10 women (40%) reported difficulty accessing therapy services and this was associated with poorer participation. Although the sample size in this study precludes definite conclusions, findings do allow for hypotheses and discussion regarding adjustment and sentinel events in the transition experiences of women with TBI.

Overwhelmingly, research on the transition phase has characterised it as a period of adjustment for individuals with TBI, calling for early intervention to prevent the onset of chronic psychological distress.² In this study the DASS was used to collect data on depression, anxiety and stress symptoms with many women with TBI noting few symptoms. However, there was significant variability in the range of total DASS scores. While some women reported no symptoms, a small number were experiencing very severe, depression (n=3), anxiety (n=3), and

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stress (n=2) at 6-months. Given the small number of participants and the presence of missing data, trends in the prevalence and trajectory of distress symptoms should be interpreted with caution.

Family members of individuals with TBI also experience difficulties with psychosocial adjustment. In contrast with other reports in the literature, fewer than 3 (18%) of caregivers in this study noted symptoms of depression, anxiety and stress that exceeded clinical cut-off scores.^{30, 31} Elsewhere, up to 51% of caregivers have been reported as experiencing depression and subjective burden.³¹ One difference is that the sample of caregivers in the current study had a higher proportion of male caregivers (9/16, 56%) compared to the study in which 51% of caregivers reported difficulties (12/49, 25%³¹). Consistent with previous research that has found gender differences in how caregivers cope with changes in family dynamics,¹⁹ these findings suggest that there may be gender differences in the psychosocial functioning of caregivers of individuals with TBI. Future studies should use a sex/gender based approach to further our understanding of how male and female caregivers experience the emotional adjustment associated with transitioning to a caregiver role.³²

Transition has also been linked to the development of self-awareness among individuals with brain injury.³³ Concurrently, some individuals also experience depression and anxiety, particularly where the awareness deficit has a psychological basis (i.e., using denial as a coping mechanism).^{34, 35} Awareness of deficits is also known to emerge with time and in this study there was greater convergence in MPAI ratings between women with TBI and caregivers following

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discharge from hospital. This may explain why average scores on the DASS for women with TBI were higher at 6-months post-discharge.^{33, 34} Alternatively, the lack of agreement between individuals and caregivers at baseline may suggest that family members over-report impairments when experiencing higher levels of depression, anxiety and stress. Regardless, the presence of emotional distress in some of the women with TBI and their family caregivers suggests the need for psychology and / or counselling services to adequately screen for and manage depression and anxiety symptoms during transition. This finding is supported by other studies in this area.²

Our preliminary analyses of the associations between sentinel events and community integration suggest this is an important area for future investigations. Due to our small sample, we investigated these relationships for only two sentinel events (having difficulty accessing therapy and return to meaningful occupation) while controlling for injury severity. Both had a significant association to community integration as measured by the participation index of the MPAI. The use of mixed effect models was important as they consider the individual variability in community integration (MPAI participation scores) and changes in scores over time.

Difficulty accessing therapy services was reported on at least one occasion during the transition period by 10 of the 25 women with TBI in our sample. Moreover, the timing of this event was extremely variable suggesting that after hospital discharge women with TBI may have an ongoing risk of not being able to access services when they need or want to. Perhaps these findings reflect a more general trend of limited community based care for individuals with TBI³⁶ or differences in the perception of service need as women have been reported to have different

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health reporting behaviours than men.^{32,37} As research in TBI has predominantly used male samples it is possible that the needs of women with TBI may not be reflected in current practices.³⁸ During the data collection period there were no transitional rehabilitation services at the recruitment sites. In addition, case management, day hospital, and outpatient rehabilitation services were noted to be limited.³⁶

Transition is associated with role change and individuals with ABI have reported frustration at the inability to engage in meaningful occupations.³⁹ In this study, women with TBI noted lower participation in work and leisure on the MPAI, despite the fact that more than half of the women in our sample (n=14/25, 56%) reported, on the SEQ, that they had in some capacity resumed meaningful activities. The frequency of this event may be attributable to the broad definition of meaningful occupation including paid work, volunteer roles and home-maker duties. Women in this sample who were able to resume meaningful activity also rated their community integration higher. Future research may test this association using more specific occupational definitions distinguishing between the type of roles and the extent to which individuals were able to return to that role in their previous capacity. This would enable rehabilitation to address the specific needs of women and men. For example, perhaps women with TBI are required to juggle multiple roles (e.g., childcare and work) causing more difficulty in these tasks, or perhaps males experience more pressure to resume work sooner.⁴⁰

A somewhat unexpected finding was that the average scores on the MPAI for women with TBI changed very little over the course of the transition period. Elsewhere,⁸ average scores on the

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MPAI-participation scale have been shown as improving throughout transition, although the sample in that study was predominantly male. This discrepancy suggests that longitudinal research is required to ascertain whether time taken to resume, or the success, in resuming meaningful activities differs for men and women. Future research may also utilise mixed methodologies to determine whether self-reported differences in participation correlate with observed functional performance.

Directions for future research

This study intended to identify the transition experiences of women with TBI due to the dearth of research in this area. Future research however, should compare the transition experiences of men and women with TBI. Sex (biological dimensions of being male or female) and gender (socially constructed dimensions of being male or female) have been inconsistently defined in research and at times used interchangeably.⁴¹ This growing understanding of the complexity of sex and gender is not routinely measured in health and rehabilitation research. Findings in this study suggest that future research should examine whether sex and gender influence the occurrence, timing, and appraisal of sentinel events. In particular events such as return to meaningful occupation, difficulty accessing therapy services, and return to independent use of transportation which were linked to community integration for women in this study. When considering events such as return to work and driving, 6-months post-discharge is a short-time frame. Therefore, considering community integration for women with TBI over a longer time-period and the extent to which transition experiences shape later outcomes is recommended.

Study limitations:

Although we recruited participants consecutively and followed them prospectively, the large proportion of potential participants that did not consent or were lost to follow-up resulted in this sample being small. Part of our sample (28%) was recruited from an acute neurosciences unit. Recruitment in these settings is very challenging given the high patient turnover, and short length of admissions. Although the small sample in the current study limits generalisability, these data present new information on an under-researched group and highlight areas for future research.

The small sample size and lack of data on the nature of cognitive and physical impairments in the sample limited our ability to undertake inferential analyses examining links between sentinel events and community integration. Univariate regression analyses were conducted due to the small number of participants, increasing the potential for type I error in the mixed effect models. However, the risk of error is mitigated to some degree by the nature of our study design resulting in prospective cohort data.^{42,43} Future research should ideally also use longitudinal designs to examine changes that occur over time, and a larger sample characterised in terms of their cognitive and physical impairments. The MPAI which measures the broad range of problems that people with ABI may encounter would be useful to include in such research.

The generalisability of these data may be compromised by the recruitment strategy whereby only two sites in a single urban setting in Australia were used. It may also be limited by observed

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differences between women with TBI lost to follow-up and the remaining sample. Moreover, only 16 caregivers were included, and the nature of their relationship to women with TBI varied. This may affect the generalisability of the findings, and the value of the proxy-report on outcome measures. Previous research has noted differences in the participant-proxy agreement based on the nature of the relationship between individuals with TBI and their caregivers.⁴⁴ **Conclusions:** Sentinel events are commonly reported and can have a significant influence on the transition process, including perceptions regarding community integration held by women with TBI. Future research using mixed methodologies should explore how perceptions of gender influence the experiences of women with TBI going through sentinel life events, including reengaging in meaningful activities and accessing rehabilitation. This will inform the establishment of individualised rehabilitation services that can facilitate successful transitions for women with TBI.

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ACCEPTED MANUSCRIPT

Table 1: Comparisons of consenting and non-consenting individuals*

	Complete cohort			Female cohort		
	Lost to follow-up	Refusal	Sample	Lost to follow-up	Refusal	Sample
	(n = 23)	(n = 60)	(n = 135)	(n = 3)	(n = 8)	(n = 25)
Gender	13	13	23	100	100	100
(% female)						
Age in years	41 ± 9.4	30.4 ± 10.9	35.6 ± 12.7	37.7 ± 6.7	33.5±14.1	33.3±10.9
(mean ± SD)						
LOS in days	47.8 ± 65.4	61.3 ± 66.4	70.2 ± 89.8	140 ± 119.7	89.4 ± 111.6	80.3 ± 86.7
(mean ± SD)						

*Eligible participants were categorised into groups those lost to follow-up, those who declined consent, those who participated (sample) and the sub-sample of women with TBI. LOS = length of hospital stay; SD = standard deviation

Table 2: Demographic characteristics of the sample

	Women with TBI (n=25)	Caregiver (n=16)
	n (%), or $M \pm SD$, range	n (%), or $M \pm SD$, range
PTA duration	27.9±29.0, 1-123	-
Length of hospitalisation	80.3±86.7, 4-394	-
Cause of injury		
MVA	13 (52)	-
Falls	10 (40)	-
Other *	2 (8)	-
Age	33±10.9, 17-50	46.5±11.4, 26-65
Education	12±3.4, 6-21	13±2.6, 10-17
Pre-injury occupation		
Paid employment	15 (60)	14 (88)
Home-maker	5 (20)	1 (6)
Student	3 (12)	0 (0)
Unemployed	2 (8)	0 (0) ‡
Gender (female)	25 (100)	7 (44)
Relation to women with TBI		
Spouse	-	8 (50)
Parent	-	6 (38)
Other †	-	2 (12)

TBI = Traumatic brain injury; M = Mean; SD = Standard deviation; PTA = Post traumatic amnesia; MVA = Motor vehicle accident; * Other = struck by falling tree branch and bicycle accident; † Other = sibling and daughter; ‡ One caregivers occupational status was unknown

Table 3: The presence and timing of sentinel events occurring in the transition of women with TBI from hospital to home

Sentinel event	Participants	Pre-discharge	Post-discharge	Total	Time to event (days)
	reporting event	occurrences n	occurrences	occurrences	
	n/25 (%)		n	n	$M \pm SD$, range
Ability to stay alone at home	23 (92%)	2	24	26	25.7 ± 27.5 , 1–99
Independence in transport use	20 (80%)	1	19	20	45.3 ± 36.5 , 1–138
Return to meaningful occupation	14 (56%)	0	15	15	66.6 ± 61.1 , 4–188
Reduced therapy access	10 (40%)	2	12	14	53.0 ± 75.4 , 1–226
Living situation change	8 (32%)	0	9	9	16.0 ± 22.8 , 0.1–63*
Return to driving	8 (32%)	0	8	8	116.3 ± 57.8 , 55–225
Financial strain	7 (28%)	2	9	11	64.9 ± 57.0 , 1–179
Relationship breakdown	6 (24%)	2	4	6	53.3 ± 52.6 , 15–127

*0.1 indicates the event occurred on the day of discharge from hospital. Pre-discharge occurrences of the event are not included in the time until event column. Some participants were unable to be interviewed until after the date of their 6-month follow-up which is why some events are reported to have occurred after 183 days. TBI = Traumatic brain injury.

Table 4: Psychosocial outcomes (mean, standard deviation, range) for women with TBI and caregivers

Measure	Pre-discharge	1-month	3-months	6-months
<u>Women</u>	(n=22)	(n=18)	(n=24)	(n=19)
MPAI total	39.9 ± 7.5, 18-51	39.6 ± 7.7, 23-50	41.1 ± 9.9, 18-55	39.9 ± 8.4, 23-54
• Abilities	34.3 ± 10.9, 7-49	37.0 ± 9.6, 7-52	38.3 ± 10.9, 20-59	37.0 ± 10.1, 20-53
• Adjustment	37.1 ± 10.4, 12-55	37.7 ± 9.8, 12-49	38.8 ± 13.7, 12-59	38.8 ± 10.1, 12-52
• Participation	42.1 ± 8.0, 20-58	37.9 ± 12.6, 4-54	38.5 ± 17.1, 4-64	39.1 ± 13.3, 20-70
DASS total	15.6 ± 20.3, 0-94	13.1 ± 13.9, 0-56	17.4 ± 23.8, 0-96	14.6 ± 15.4, 0-60
• Depression	5.2 ± 7.7, 0-30	4.3 ± 5.9, 0-24	6.0 ± 9.9, 0-36	5.5 ± 6.4, 0-24
• Anxiety	3.9 ± 7.7, 0-36	3.9 ± 5.5, 0-24	4.7 ± 7.8, 0-32	3.2 ± 5.7, 0-20
• Stress	6.5 ± 7.4, 0-28	4.9 ± 4.3, 0-18	6.7 ± 8.3, 0-32	5.8 ± 6.2, 0-20
<u>Caregivers</u>	(n=12)	(n=16)	(n=14)	(n=9)
MPAI total	44.8 ± 4.7, 37-51	37.0 ± 16.7, -5-52	35.6 ± 18.7, -5-53	40.6 ± 10.8, 19-56
• Abilities	41.8 ± 7.2, 25-52	34.6 ± 12.1, 4-50	37.9 ± 14.6, 4-56	40.2 ± 11.0, 18-53
• Adjustment	44.3 ± 4.4, 35-51	37.5 ± 17.2, 6-53	37.3 ± 19.4, 6-54	36.9 ± 15.3, 12-56
• Participation	45.1 ± 5.7, 35-53	40.4 ± 9.5, 22-50	37.3 ± 16.0, 10-63	38.6 ± 12.9, 22-58
DASS total	14.8 ± 14.9, 0-41	14.1 ± 14.9, 0-56	6.1 ± 8.1, 0-22	10.7 ± 9.7, 0-24
• Depression	4.3 ± 7.3, 0-25	3.9 ± 4.9, 0-16	1.5 ± 1.9, 0-4	2.9 ± 2.5, 0-6
• Anxiety	1.8 ± 2.2, 0-7	1.9 ± 2.4, 0-8	0.6 ± 0.9, 0-2	0.7 ± 0.9, 0-2
• Stress	8.8 ± 8.5, 0-24	8.3 ± 8.4, 0-32	4.1 ± 5.9, 0-16	7.1 ± 6.5, 0-16

TBI = Traumatic Brain Injury; MPAI = Mayo Portland Adaptability Inventory, scores presented are standardised *T-scores*. *T-scores*: 30-40 = mild impairment, 40-50 = mild-moderate impairment, 50-60 = moderate to severe impairment, >60 = severe impairment; DASS = Depression Anxiety Stress Scale. Depression scores >9, anxiety scores >7 and stress scores >14 indicate clinically significant levels of the respective symptoms.

Highlights:

- Few studies consider the hospital to home transition process for women with TBI
- We collected prospective data from 25 women at discharge and then 1,3 & 6-months later
- We describe sentinel life events reported by women with TBI during the transition phase
- Two events, reduced therapy access & return to activity, influenced community integration
- About 1/3 of women had clinically significant depression, anxiety or stress symptoms
- Examining life events (e.g., returning to work) may facilitate successful transitions

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Sentinel events during the transition from hospital to home: a longitudinal study of women with a traumatic brain injury

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