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Caregivers of Adults With Traumatic Brain Injury: The Emotional Impact of Transition From Hospital to Home

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PPrimary Objective: To explore levels of depression, anxiety, stress and strain symptomatology experienced by caregivers of adults with traumatic brain injury (TBI) during the phase of transition from hospital to home. *Research Design:* Prospective study with data collected at three time-points: pre-discharge, 1-month post-discharge, and 3-months post-discharge. *Methods and Procedures:* Twenty-nine caregivers of adults with TBI (mean age 48 years), recruited on patient discharge from rehabilitation, completed the Caregiver Strain Index and the Depression, Anxiety and Stress Scale at the three time points. *Results:* Paired *t* tests showed significantly lower levels of caregiver strain at one month compared to pre-discharge, and significantly less strain and depression symptoms at 3-month follow-up compared to pre-discharge. Non-significant reductions were observed in level of stress and anxiety across the follow-up time points. Independent group *t* tests found that female caregivers experienced greater strain than male caregivers at 3 months post-discharge, and caregivers who were immediate family members of the patient experienced greater anxiety than those who were spouses/partners of the patient at 1-month follow-up. *Conclusions:* The rate of depressive symptoms in caregivers of people with TBI was greater than the general population, and strain was prevalent during the transition period. The results suggest more specific caregiver support and preparation is needed before patient discharge from hospital, and that adequate time spent in rehabilitation is beneficial for caregiver wellbeing.

Keywords: rehabilitation, brain injury, discharge, anxiety, depression, stress

The impact of traumatic brain injury (TBI) is generally multifaceted, and may include diminished physical and cognitive abilities, and alterations to personality behaviour and emotions (Khan, Baguley, & Cameron, 2003; Rogers & Read, 2007). This may subsequently disrupt the individuals' lifestyle, independence, and interpersonal relationships, and has a major impact upon an

individual's ability to live a productive life in the community (Khan et al.; Olofsson, Andersson, & Carlberg, 2005; Rogers & Read). After discharge from hospital, many individuals with TBI return home to live in the community with the support of family members, who in many instances assume the primary caregiving role (Grant, Weaver, Elliott, Bartolucci, & Giger, 2004; Hankey, 2004;

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Low, Payne, & Roderick, 1999; McPherson, Pentland, & McNaughton, 2000). Caregiving is a multilayered concept (McCullagh, Brigstocke, Donaldson, & Kalra, 2005), with assistance being provided at different levels of activity, including basic self-care needs such as eating and bathing, as well as instrumental activities of daily living (IADL) such as cooking, cleaning and providing transport. Caregivers also provide emotional and psychological support during social reintegration, such as accompanying individuals' on community and social outings (Hankey, 2004). Given the central role that families have in the reintegration of individuals with TBI, it is important to consider the wellbeing of family caregivers and monitor levels of caregiver strain, especially during the transition phase from hospital to home (Fraser, 1999; Hankey, 2004; McCullagh et al., 2005).

Caregiving is the act of providing assistance to an individual with whom the caregiver has a personal relationship (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Caregiver burden is defined as the strain or load borne by a person who cares for an elderly, chronically ill, or disabled family member or other person (Stuckey, Neundorfer, & Smyth, 1996). It has been described as a term that encompasses the emotional, physical and financial toll of care provision (George & Gwyther, 1986). Research suggests that caregiver burden is prevalent among family caregivers of individuals with TBI and has been shown to impact significantly on caregiver wellbeing and quality of life (Elliot, Shewchuk, & Richards, 2001). For example, Novack, Bergquist, Bennett and Gouvier (1991) assessed caregiver distress following TBI ($n = 45$) and found clinical levels of anxiety in one third of caregivers at rehabilitation admission that diminished by discharge, whereas the frequency of depression was low. It appeared that low rates of clinical depression (0%) and anxiety (8%) were maintained at 3 months after discharge, but follow-up data were missing for 40% of the sample (Novack et al.). In contrast, Ergh, Rapport, Coleman and Hanks (2002) found clinically significant levels of anxiety, depression and poor social adjustment to be affecting 30–50% of caregivers ($n = 60$) 1 year post stroke. Similar findings in relation to caregivers of people with TBI have been reported (Mitchley, Gray, & Pentland, 1996). There is a visible gap in the literature with regard to the effect of patients' transition from hospital to home on the caregivers of patients with TBI. This study examines changes in caregiver burden or strain and emotional wellbeing during the initial few months after the patient is discharged from brain injury rehabilitation.

Predictors of Caregiver Burden

Conflicting evidence exists in the literature with reference to factors that are predictive of levels of caregiver burden. Some studies report that burden is closely related to the wellbeing of the caregiver, while others attribute burden to the characteristics of the individual with brain injury. For example, McCullagh et al. (2005) followed 232 individuals with stroke and their caregivers at 3 and 12 months post-stroke and found that advancing age, high anxiety levels, greater level of patient dependency and lack of family support impacted on caregiver burden. Furthermore, level of disability, age, gender and characteristics of the patient were found to affect caregiver quality of life.

Tooth, McKenna, Barnett, Prescott, and Murphy (2005) interviewed individuals with stroke and caregivers 6 months ($n = 71$) and 12 months ($n = 57$) after discharge from hospital and found that caregivers were affected by changes to life plans, the behaviour of the individual with stroke, and the burden associated with caregiving. At both 6 and 12 months post-discharge, caregivers' physical and mental health was poorer than population norms (Tooth, et al.). A study by Bugge, Alexander, and Hagan (1999) on 153 caregivers (with a representative population cross-section) at 1, 3 and 6 months post-stroke, found that the amount of time spent with and caring for the post-stroke individual was significantly associated with high levels of caregiver strain. Poor caregiver physical and mental health was also related to caregiver strain (Bugge et al.). Other factors that have been reported as impacting upon caregiver burden include the severity of physical impairment and the behavioural, emotional and cognitive changes of the individual with an acquired brain injury (ABI) (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001).

Effects of Caregiver Burden

There is considerable evidence to suggest that caregivers of individuals with an ABI experience negative psychological outcomes that are inherently related to their caregiving role. Research indicates that caregivers are at substantial risk of clinical depression (Chumbler, Rittman, Van Puymbroeck, Vogel, & Qnin, 2004; Han & Haley, 1999; King et al., 2001), anxiety (Marsh, Kersel, Havill, & Sleigh, 1998a), reduced quality of life (McCullagh et al., 2005), burn-out (van den Heuvel et al., 2001), decreased family functioning (Douglas & Spellacy, 1996; Gan, Campbell, Gemeinhardt, & McFadden, 2006), and relationship breakdown (Blais & Boisvert, 2005). Despite this, prevalence rates reported in the literature are

inconsistent. For example, at 6-months post-discharge, King et al. (2001) found a 69% prevalence of depression in caregivers of people with stroke ($n = 136$), whereas Bugge et al. (1999) found 37% of caregivers of people with stroke ($n = 110$) showed signs of depression. Marsh et al. (1998b) found that caregiver burden was associated with high rates of anxiety (60%), changes in sleep patterns (54%), reduced levels of personal privacy (53%), social isolation and an increased use of prescription and non-prescription drugs at 1-year post traumatic brain injury.

Effect of Transition on Caregivers

While the literature acknowledges the prevalence of burden among caregivers of individuals with TBI and its effects on their general health and wellbeing, little is known about levels of caregiver burden experienced during the initial transition phase from hospital to home. Schlossberg (1984) described transition as the course of one life phase, condition or status to another that occurs over time and involves a change in roles, identities, patterns or abilities. For individuals with TBI and their caregivers, a key transition occurs when the individual leaves the hospital setting and returns home, often for the first time since the onset of their injury. The transition phase has been described as initially chaotic and characterised by a change in family relationships, with caregivers having difficulty coping with new responsibilities and experiencing feelings of hopelessness (Bull, 1992; Fraser, 1999).

Although the literature is clear in highlighting the prevalence of caregiver burden and its association with caregiver wellbeing, few studies have specifically investigated levels of caregiver burden over the course of transition from hospital to home (excluding, Norup, Siert, & Mortensen, 2010). Furthermore, the literature typically focuses on individuals with stroke aged over 65 years (Chumbler et al., 2004; Kalra et al., 2004; McCullagh et al., 2005; Olofsson et al., 2005; Tooth et al., 2005), rather than younger people with TBI. Caregivers of this group are likely to have different types of relationships and life roles that may affect their experiences. In view of these issues, the purpose of the present study was to perform an exploratory investigative analysis into levels of caregiver burden and emotional wellbeing during the initial 3 months following hospital discharge. The study aimed to: (1) to determine the extent of clinically significant levels of symptoms of depression, anxiety, stress and strain in caregivers of young people with TBI over the first 3 months after discharge from rehabilitation; (2)

to examine changes in levels of depression, anxiety, stress and strain symptoms in caregivers over the first 3 months after discharge; and (3) to identify the factors that are related to higher levels of depression, anxiety, stress and strain symptoms in caregivers of individuals with TBI.

Method

Design

The study employed a prospective, longitudinal research design with data collected at three time points: pre-discharge, 1-month and 3-months post-discharge.

Participants

Participants were the caregivers of younger individuals with TBI (less than 65 years) who were recruited to participate in a separate study on the perspectives and experiences of individuals with ABI during the transition from hospital to home. The individuals with TBI were recruited prior to discharge from an inpatient brain injury rehabilitation unit at a major metropolitan hospital on a consecutive discharge basis, according to the following inclusion criteria: (1) diagnosis of TBI as documented in a medical report, (2) adequate verbal communication skills to participate in an interview, and (3) the provision of informed consent. Individuals were excluded if they had a pre-morbid neurological condition or psychiatric disorder.

Individuals with TBI who consented to participate were asked to nominate a primary caregiver to participate in the present study. Caregivers were invited to participate in the study according to the following inclusion criteria: (1) nominated caregiver of an individual with TBI who has a planned discharge date and is expected to return home upon discharge, (2) aged 18 years or over and, (3) adequate English literacy skills to complete a written questionnaire. Caregiver participants were excluded if they had a medical condition that would impact on their ability to participate in the study.

During the time of participant recruitment, a total of 119 individuals with TBI were discharged from the site of participant recruitment. Of these, 22 self-discharged against medical advice, 31 did not consent to participate and 13 individuals did not meet the inclusion criteria. Caregivers of these individuals were not approached to participate in the present study. In total, 39 caregiver participants met the inclusion criteria and consented to participate. Ten of these participants did not complete the study, and were excluded from the analyses. Caregivers who did not complete the study

were significantly younger than those who did complete the study. The final sample included 29 patients (23 males, ranging in age from 17 to 63 years [$M = 35$, $SD = 15$]), and 29 caregivers (23 females, ranging in age from 27 to 61 years [$M = 48$, $SD = 9$]).¹ Caregivers were recruited over a period of 16 months. The relationship of the caregivers to patients with TBI included 11 mothers (38%), nine wives (31%), four unmarried partners (14%), four fathers (14%), and one daughter (3%). The caregiver participants had a range of educational levels with six (21%) having 10 or less years of schooling, five (17%) completed high school, seven (24%) with trade qualifications, six (21%) with undergraduate university degrees, four (14%) with postgraduate degrees, and one did not provide their educational history (3%). Twenty-five caregivers and 28 patients were employed at the time of injury (one caregiver and one patient did not provide their occupational history). Of the caregivers who were employed 4 (14%) were managers/administrators, 9 (31%) were professionals, 5 (17%) were skilled workers, and 3 (10%) were in unskilled employment. Of the patients who were employed 5 (17%) were managers/administrators, 3 (10%) were profes-

sionals, 12 (41%) were skilled workers, 2 (7%) were semi-skilled workers, and 6 (20%) were in unskilled employment. Table 1 provides additional information about the individuals with TBI including their level of disability at the time of discharge from hospital.

Outcome Measures

Two standardised questionnaires were used to obtain quantitative data on levels of strain, depression, anxiety and stress symptomatology experienced by caregivers of individuals with ABI at each of the three time points during the transition from hospital to home.

Depression, Anxiety and Stress

The Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) is a self-report questionnaire designed to measure levels of depression, anxiety and stress symptomatology. The measure consists of three subscales (i.e., depression, anxiety, and stress). Each item is rated by the participant who considers the statements in relation to the past week. Scores are rated on a 4-point severity/frequency scale ranging from 0–3, with 0 indicating

TABLE 1
Summary of Injury-related Information for Individuals with TBI ($n = 29$)

| | Freq (%) or mean (SD) range |
|---|------------------------------------|
| Length of stay in rehabilitation (days) | 93.55 (74.35) 14–318 |
| Length of stay in hospital (days) | 149.62 (143.46) 46–776 |
| Cause of TBI | |
| MVA | 12 (41%) |
| MBA | 2 (7%) |
| Fall | 5 (17%) |
| Car vs. pedestrian | 2 (7%) |
| Assault | 4 (14%) |
| Work accident | 3 (10%) |
| Helicopter accident | 1 (3%) |
| Initial GCS score ^a | 8.34 (3.98) 3–15 |
| Length PTA (days) ^b | 49.15 (35.62) 12–173 |
| DRS scale (admission) | 7.66 (3.45) 3–21 |
| DRS (discharge) | 4.69 (1.56) 2–8 |
| FIMTM total score (admission) | 81.66 (32.50) 23–121 |
| FIMTM motor score (admission) | 60.66 (27.55) 14–91 |
| FIMTM cognition score (admission) | 20.31 (5.84) 7–30 |
| FIMTM total score (discharge) | 115.86 (10.19) 77–125 |
| FIMTM motor score (discharge) | 87.28 (7.25) 57–91 |
| FIMTM cognition score (discharge) | 28.59 (4.08) 20–34 |

Note: TBI = traumatic brain injury; MVA = motor vehicle accident; MBA = motorbike accident; DRS = Disability Rating Scale; GCS = Glasgow Coma Scale; PTA = post-traumatic amnesia; FIMTM = Functional Independence Measure
^a $n = 25$; ^b $n = 26$

that the item did not apply to the participant at all over the past week and 3 indicating that the item applied very much or most of the time. Scores on each scale ranging from 0 to 42, with higher scores indicating higher levels of depression, anxiety and stress. Clinical cut-offs recommended by Lovibond and Lovibond (1995) are scores < 9 = normal, 10–13 = mild, 14–20 = moderate, 21–28 = severe, and > 28 = extreme.

The DASS has sound psychometric properties (Antony, Beiling, Cox, Enns, & Swinson, 1998); the internal consistency has been demonstrated as high for the three scales (anxiety: $\alpha = .90$; depression $\alpha = .95$; stress $\alpha = .93$). The construct validity of the DASS was supported by correlation the Beck Anxiety Inventory ($r = .81$) and the Beck Depression Inventory ($r = .74$) (Antony et al., 1998).

Level of Strain

The Caregiver Strain Index (CSI; Robinson, 1983) was used to assess the level of burden/strain experienced by caregivers. The CSI is a 12-item self-rated questionnaire that measures strain related to the provision of care in five major domains: (1) employment, (2) financial, (3) physical, (4) social, and (5) time. Responses are rated on a dichotomous scale (yes or no) with positive responses to seven or more of the items on the index indicating a clinically significant level of strain. Sound psychometric properties have been reported for the CSI with a high level of internal consistency ($\alpha = 0.86$) and construct validity supported by significant correlations with other measures of caregiver wellbeing (Robinson, 1983).

Injury-Severity Variables

The following injury severity data were collected: initial Glasgow coma score (GCS) score (Teasdale & Jennett, 1974), length of post-traumatic amnesia (PTA) (Westmead PTA scale: Marosszky, Ryan, Shores, Batchelor & Marosszky, 1997); admission and discharge Functional Independence Measure™ (FIM™) scores (Uniform Data System for Medical Information, 1997); and admission and discharge Disability Rating Scale (DRS) scores (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982). The FIM™ is an 18-item scale that measures a person's independence in activities of daily living and is divided into motor and cognitive components with higher scores indicative of higher functioning. The Disability Rating Scale (DRS) measures a person's general functional ability over the course of their recovery on a 30-point scale with lower scores indicative of higher functioning. Scores of three and under are considered functional, while the maximum score

of 29 indicates an extreme vegetative state (Rappaport et al., 1982).

Procedure

The ethics committees of the site of participant recruitment and university approved the study. Caregiver participants were approached by the occupational therapist treating their family member with TBI, who provided an overview of the study and asked if the caregiver would be willing to be contacted by a member of the research team. Caregivers were then contacted and written informed consent obtained. Informed consent was also sought from the individual with TBI in order to access their medical record.

Participants completed the two questionnaires at each time point (pre-discharge, and 1- and 3-months post-discharge). The initial pre-discharge data collection occurred at the hospital during the week prior to their family member's discharge from hospital. The 1- and 3-month follow-up assessments were conducted either by face-to-face meetings at a location of the participant's choice or by telephone according to the geographical location of the participant and/or their personal preference. The medical records of the individual with TBI were accessed during the week after their discharge from hospital to collect demographic and injury related information.

Data Analysis

The two questionnaires were scored and data were entered into the statistical software package SPSS (version 16.0) along with demographic and injury-related information. Descriptive and exploratory analyses were conducted to screen for missing data, examine distributions and address the first research aim regarding levels of caregiver burden over the transition period.

The second research aim was addressed using paired sample *t* tests to examine changes in symptoms of depression, anxiety, stress, and strain over time. Changes in DASS and CSI scores were analysed separately using planned comparisons between pre-discharge and 1-month post-discharge scores, and between pre-discharge and 3-months post-discharge scores.

To address the third aim of identifying the patient and caregiver characteristics associated with caregiver wellbeing, Spearman's rank correlations conducted between DASS and CSI scores and continuous variables (i.e., caregiver age, patient age, length of stay in hospital, length of stay in rehabilitation, initial GCS, length PTA, discharge FIM™ motor scores, and discharge FIM™ cognition scores). For categorical variables (i.e., caregiver

gender, patient gender, relationship of caregiver to patient, relationship status of caregiver, caregiver education level, DRS category on discharge) variables were dichotomised if necessary and independent groups *t* tests were conducted to investigate between-group differences on DASS and CSI scores. Levene's tests were used to determine whether the assumption of equal variance was accepted or rejected. Significance was determined using an alpha level of 0.05.

Results

Levels of Depression, Anxiety, Stress and Strain

As shown in Table 2, mean DASS (depression, anxiety, and stress scores) were higher in the current caregiver sample than the general adult community at pre-discharge. Levels of depression, anxiety, and stress symptoms and CSI scores decreased initially between pre-discharge levels and 1-month post-discharge and then either remained stable or showed a slight decrease at 3-months post-discharge.

At pre-discharge, more caregivers (27%) reported some level of depressive symptoms (i.e., mild, moderate, severe, or extremely severe) than reported in the general adult community (18%; Crawford & Henry, 2003); 12% of caregivers reported depressive symptoms at both 1- and 3-month follow-up. The percentage reporting anxiety symptoms was greatest at pre-discharge (13%), which is slightly higher than observed in the general adult community (11%; Crawford & Henry, 2003). Anxiety symptoms decreased to 3% and 6% at the 1- and 3-month follow-ups, respectively. Elevated levels of stress symptoms were reported by 45% at pre-discharge, increasing to 48% at 1-month follow-up, and dropping to 27% at 3-months post-discharge. Levels of stress

reported within this caregiver sample were higher than observed in the general community (20%; Crawford & Henry, 2003) at all three time points. At pre-discharge, 69% ($n = 20$) of caregivers were experiencing abnormal levels of caregiver strain on the CSI (i.e., scores of 7 or higher). This decreased to 41% ($n = 12$) by 1-month post-discharge but increased again by 3-months post-discharge with 52% ($n = 15$) experiencing abnormal levels of caregiver strain.

Changes Over Time

Paired *t* tests were used to identify statistically significant changes between the study variables at pre-discharge and the two additional time points (see Table 3). The reduction in caregiver strain between pre-discharge ($M = 8.21$, $SD = 2.62$) and 1-month follow up ($M = 6.66$, $SD = 3.40$) and pre-discharge and the 3-month follow up ($M = 6.83$, $SD = 3.36$) were significant. A significant reduction in depressive symptoms was observed between pre-discharge ($M = 7.41$, $SD = 9.34$) and the 3-month follow up ($M = 3.93$, $SD = 8.03$). The difference in depression symptoms between pre-discharge and 1-month ($M = 5.21$, $SD = 7.57$) was not significant. The difference between pre-discharge ($M = 3.76$, $SD = .92$) and 3-month ($M = 1.93$, $SD = 3.76$) anxiety, and pre-discharge ($M = 11.14$, $SD = 9.12$) and 3-month ($M = 7.83$, $SD = 8.68$) stress did not reach the predetermined level of significance. The reduction in anxiety score between pre-discharge and 3-months post-discharge was statistically significant, $t(24) = 2.18$, $p = .04$, while the reduction in stress score between the pre-discharge and 3-month post-discharge assessments approached significance, $t(24) = 2.04$, $p = .053$. Similarly, CSI scores were found to decrease significantly between the pre-discharge and 1-month post-discharge assessments $t(24) =$

TABLE 2

Mean DASS and CSI Levels during Transition from Hospital to Home.

| Variable | Pre-discharge M (SD) ($n = 29$) | 1 month post-discharge M (SD) ($n = 29$) | 3 months post-discharge M (SD) ($n = 29$) | Normative data ^a ($n = 1, 771$) |
|------------|---|--|---|--|
| DASS | | | | |
| Depression | 7.4 (9.3) | 5.2 (7.6) | 3.9 (8.0) | 5.5 (7.48) |
| Anxiety | 3.8 (5.0) | 2.5 (3.5) | 1.9 (3.8) | 3.6 (5.39) |
| Stress | 11.1 (9.1) | 10.7 (10.5) | 7.8 (8.7) | 9.3 (8.04) |
| CSI | 8.2 (2.6) | 6.7 (3.4) | 6.8 (3.4) | — |

Note: DASS = Depression, Anxiety and Stress Scale; CSI = Caregiver Strain Index

^a Normative data for the DASS are based upon a large sample (mean age = 40.9 years, $SD = 15.9$) from the United Kingdom general adult population (Crawford & Henry, 2003).

TABLE 3

Paired Sample *t* tests Comparing PredischARGE and One-Month, and PredischARGE and Three-Month Scores for Emotional Distress and Caregiver Strain (*n* = 29)

| Comparison: | <i>df</i> | <i>t</i> | <i>d</i> ^a | <i>p</i> |
|--|-----------|----------|-----------------------|----------|
| Pre-discharge and 1 month | | | | |
| Depression (DASS) | 28 | 1.42 | .27 | .17 |
| Anxiety (DASS) | 28 | 1.30 | .28 | .20 |
| Stress (DASS) | 28 | .25 | .04 | .80 |
| Strain (CSI) | 28 | 2.87** | .50 | < .01 |
| Comparison: Pre-discharge and 3 months | | | | |
| Depression (DASS) | 28 | 2.19* | .40 | .04 |
| Anxiety (DASS) | 28 | 1.74 | .41 | .09 |
| Stress (DASS) | 28 | 1.86 | .37 | .07 |
| Strain (CSI) | 28 | 2.49* | .45 | .02 |

Note: DASS = Depression Anxiety and Stress Scale, CSI = Caregiver Strain Index, TBI = traumatic brain injury
^a Effect size (*d*) was calculated for dependent (within groups) analyses using ClinTools Effect Size Generator — Professional Edition Version 4.1 (Devilley, 2007).
p < .05. ***p* < .01

2.49, *p* = .02, however this difference was no longer significant at 3-months post-discharge.

Factors Associated With Level of Depression, Anxiety, Stress and Caregiver Strain

Caregiver age, patient age, length of stay in rehabilitation, length of stay in hospital, initial GCS, length of PTA and FIM™ discharge scores of the patient were not significantly correlated with depression, anxiety, stress, or caregiver strain at any of the three time points (see Table 4). However, the positive correlation between caregiver age and caregiver strain represented a medium effect at 1-month post-discharge (Cohen, 1988). A medium positive correlation was evident between patient age and caregiver stress at the 3-month follow-up. Medium positive correlations were also present between both length of stay in rehabilitation and length of stay in hospital with caregiver strain at the 3-month follow-up, as well as length of PTA and caregiver anxiety at the 3-month follow-up. Additionally, a medium negative correlation between initial GCS and pre-discharge caregiver stress was recorded.

Independent groups *t* tests were used to determine the effect of categorical caregiver and patient variables on caregiver well being at all three time points. Categorical independent variables include: caregiver gender; patient gender; level of caregiver education (up to 12 years [*n* = 12] versus those with higher education training [*n* = 16]); caregiver relationship to patient (spouses/partners [*n* = 13] versus immediate family members [*n* = 16]) and; level of patient disability (DRS scores of 3 or less [*n* = 8]

versus discharge DRS scores greater than 3 [*n* = 21]).² No significant differences were found for gender of the patient, or level of caregiver education on levels of depression, anxiety, stress, or caregiver strain at any time point (i.e., pre-discharge, 1-month, or 3-months post discharge). Female caregivers (*M* = 7.48, *SD* = 3.06) experienced significantly more strain than male caregivers (*M* = 4.33, *SD* = 3.56) at the 3-month follow-up, *t* (27) = 2.17, *p* = .04, indicating a large effect (*d* = .95).² Family members (*M* = 3.75, *SD* = 4.22) experienced significantly more anxiety than spouses/partners (*M* = 1.08, *SD* = 1.50) at one-month post-discharge, *t* (19.43) = -2.36, *p* = .03. This difference represented a large effect, *d* = -.84.² Caregivers of individuals with low DRS scores (i.e., less disability) (*M* = .75, *SD* = .89) experienced significantly less depression at three month post discharge than caregivers of individuals with greater disability (*M* = 5.14, *SD* = 9.18), *t* (20.95) = -2.17, *p* = .04. This difference in level of depression represented a small effect (*d* = .11).²

Discussion

This study aimed to investigate the level of burden and emotional wellbeing in caregivers of individuals with TBI. Of specific interest was how levels of caregiver strain, depression, anxiety and stress changed during the initial three months following hospital discharge, and how patient and caregiver characteristics influenced these levels. The first aim was to examine whether caregivers experience clinically significant symptoms of depression, anxiety, stress, and strain. Results showed that, compared to normative data (Crawford &

TABLE 4

Spearman's Rank Correlations between Caregiver Well-being Variables and Continuous Demographic and Injury Severity Variables

| | Caregiver age (n = 27) | Patient age (n = 29) | LOS rehab (n = 29) | LOS hospital (n = 29) | Initial GCS (n = 25) | Length of PTA (n = 26) | Discharge FIM™ Motor (n = 29) | Discharge FIM™ Cognition (n = 29) | Discharge FIM™ Total (n = 29) |
|--------------------------------|------------------------------|----------------------------|--------------------------|-----------------------------|----------------------------|------------------------------|--|--|--|
| Pre-discharge | | | | | | | | | |
| Depression | .11 | -.09 | -.01 | .04 | -.23 | .08 | .14 | -.03 | .04 |
| Anxiety | -.08 | .14 | -.23 | -.14 | -.29 | .11 | .13 | .02 | -.02 |
| Stress | .14 | .06 | .01 | .04 | -.34 | -.03 | .03 | -.18 | -.13 |
| CSI | .17 | -.10 | .15 | .12 | -.03 | .22 | -.04 | .01 | -.01 |
| 1 month post-discharge | | | | | | | | | |
| Depression | .25 | .01 | .08 | .04 | -.22 | .20 | -.02 | -.21 | -.18 |
| Anxiety | .26 | -.10 | .02 | .09 | -.29 | .16 | .04 | -.02 | .02 |
| Stress | .28 | .06 | -.03 | -.10 | -.14 | -.06 | -.08 | .19 | -.05 |
| CSI | .31 | .22 | .16 | .10 | -.14 | .10 | -.15 | < .01 | -.03 |
| 3 months post-discharge | | | | | | | | | |
| Depression | .13 | .24 | .20 | .13 | .14 | .26 | -.10 | -.14 | -.14 |
| Anxiety | -.04 | .07 | .25 | .26 | -.17 | .31 | -.03 | -.05 | -.07 |
| Stress | -.01 | .32 | .21 | .15 | .15 | .17 | -.18 | .13 | < .01 |
| CSI | .10 | .23 | .36 | .34 | -.11 | .25 | -.27 | -.15 | -.24 |

Note: LOS = Length of stay; GCS = Glasgow Come Scale; PTA = Post traumatic amnesia; FIM™ = Functional Independence Measure, CSI = Caregiver Strain Index. Effect sizes for correlations can be interpreted as: .10 = small; .30 = medium and; .50 = large (Cohen, 1988). * $p < .05$, ** $p < .01$

Henry, 2003), caregivers reported elevated levels of depression, anxiety, and stress pre-discharge, with stress remaining elevated throughout the period of transition from hospital to home.

Specifically, prevalence of depressive symptoms (27%), anxiety (13%) and stress (45%) (ranging from mild to extremely severe) in caregivers was high at pre-discharge compared to reported prevalence in the general adult community (reported at 18%, 11%, and 20%, respectively: Crawford & Henry, 2003). Levels of depression and anxiety symptomatology decreased at 1-month and 3-months post-discharge to rates lower than reported within the general population. Levels of self-reported anxiety symptoms were not as high as previously found for caregivers of people with traumatic brain injury at a mean of 4.8 years post-injury (Ergh et al., 2002).

Caregivers reported stress and strain more frequently than depression and anxiety. Stress and strain are closely linked constructs and are not well differentiated. The DASS (Antony et al., 1998), however, conceptualises stress as a subjective emotional experience, for example the occurrence of nonspecific arousal, and an inability to relax and agitation (e.g., 'I find it hard to wind down'). In contrast strain, as measured by the CSI

(Robinson, 1983), focuses more on subjective activity/participation experience (e.g., 'there have been work adjustments'). A proportion of caregivers reported mild to extremely severe levels of stress at pre-discharge (45%); 1-month post-discharge (48%); and 3-months post-discharge (27%). These rates are higher than observed within the general adult community (20%: Crawford & Henry, 2003). In addition, many caregivers reported increased levels of strain at pre-discharge (69%); 1-month post-discharge (41%); and 3-months post-discharge (52%). These rates are higher than those found in caregivers of patients with brain tumours (26%) and general cancer patients (22%; Ownsworth, Henderson, Chambers, & Shum, 2009). These findings suggest a high prevalence of both stress and strain in caregivers of individuals with TBI during the transition phase from hospital to home. High levels of caregiver burden may be understood as a response to role changes and to the emotional, practical and financial difficulties faced by the family (George & Gwyther, 1986), which, from the present findings, appear to be greater just prior to discharge as compared to post-discharge.

The second aim of the study was to investigate the longitudinal changes in caregiver wellbeing

during the first 3 months after discharge. Levels of depressive symptoms decreased following discharge. However, the reduction in depressive symptoms only reached significance at the 3-month follow-up. Previous research into caregiver depression in the context of brain injury is mixed. Elliot et al. (2001) reported increases in caregiver depression when patients were discharged from rehabilitation services. However, King et al. (1998) reported that caregiver depression decreased over time from discharge to 6–10 weeks post discharge. The results from the current study suggest that levels of depression in caregivers may improve, potentially as the caregiver is relieved that their family member is home.

Anxiety symptoms also showed a pattern of decreasing between pre-discharge 1-month and 3-months post-discharge. These results are in contrast to those of Elliot et al. (2001), who found an increase in caregiver anxiety between hospital admission and 1-month post-discharge, and a decrease in caregiver anxiety between 1 and 6 months post-discharge. Differences in timing of assessments may account for this disparity. It is possible that anxiety peaks at the time of discharge from hospital that is when the current study first assessed caregivers. The pattern of change in anxiety was similar to that of depression, and may have been influenced by similar factors such as initial caregiver relief at having their family member home.

The pattern of change for caregiver stress symptoms was similar to the pattern observed for depression and anxiety. Stress was elevated and remained relatively stable between pre-discharge and the 1-month follow-up. There was a near significant reduction in stress symptoms between pre-discharge and 3-months post-discharge. To our knowledge, previous research has not explored change in levels of caregiver stress. Results of the present study suggest that the most stressful time for caregivers is immediately prior and during the first months post-discharge; perhaps due to fear of the unknown or the stress of preparing for their family members' homecoming (Turner, Fleming, Cornwell, & Ownsworth, 2008).

The pattern of change in caregiver strain differed from that of depression, anxiety and stress. Levels of caregiver strain decreased significantly between pre-discharge and 1-month post-discharge, and pre-discharge and 3-month follow-up. However, strain appeared to remain relatively stable between the two follow-up time-points. Previous research has found that levels of caregiver strain remained steady over time (Bugge et al., 1999); however, such data were collected at 6

and 12 months post-discharge. Differences in results may therefore reflect the different expectations experienced by caregivers at different times. As with depression and anxiety, it is possible that the initial decrease in strain scores is due to a 'honeymoon' period, with the caregiver continuing to feel motivated and energetic. Stability rather than a reduction in caregiver strain between 1 and 3 months post-discharge may reflect an increase in fatigue, or decreased offers of support (McCullagh et al., 2005) as the initial period of crisis passes.

A third aim of the study was to investigate caregiver and patient characteristics associated with levels of caregiver burden. In contrast to previous research (McCullagh, et al., 2005; Nabors, Seacat, & Rosenthal, 2002) advancing caregiver age was related to strain at 1-month post discharge. Nabors et al. (2002) reported that when fewer family needs are met (e.g., emotional, instrumental, and social), the greater the perceived burden of caregiving. Furthermore, younger caregivers reported significantly fewer needs being met than older caregivers (Nabors et al.). Caregivers who did not complete the current study were significantly younger than those who did. Potentially, these individuals may have been experiencing substantially more strain, thus impeding their ability to participate. This may in part explain the current findings.

An association between patient age and caregiver stress was observed at 3-months post-discharge, with greater symptoms associated with increasing age of the patient. This may be due to reductions in the caregiver's quality of life, which has been associated with both advancing caregiver and patient age at three months and one year post-stroke (McCullagh et al., 2005). In addition, length of patient stay in rehabilitation and hospital was related to caregiver burden, with an increased length of stay associated with greater levels of caregiver strain at 3-months post-discharge. This may reflect a greater level of assistance necessitated by those who require longer stays in hospital and/or rehabilitation, in turn impacting upon the caregivers own level of activity and participation. Although representing medium to large effects, these associations failed to reach the predetermined level of significance, potentially due to the smaller sample size.

Prior research has observed no significant differences in levels of emotional adjustment and perceived burden when comparing caregiver gender, age, or type of relationship with patient (e.g., spousal vs. parental; Davis, et al., 2009; Kreutzer, et al., 2009; Norup, et al., 2010).

Consistent with these findings, the current study found no association between caregiver ages. However, female caregivers experienced significantly greater strain at 3-months post-discharge than male caregivers. These results are consistent with Yee and Schulz's (2000) literature review of heterogeneous caregiver groups (e.g., caregivers to the elderly, disabled, cancer, and dementia patients). Their review revealed that female caregivers tend to experience greater levels of emotional distress and reductions in life satisfaction compared to their male counterparts. In addition, caregivers who were not in a spousal relationship experienced significantly higher levels of anxiety symptoms at 1-month post-discharge than those in spousal relationships. This may reflect perceptions of impending changes in living arrangements, for example, with the possibility that an injured son or daughter may need to return to the parental home.

The findings on the nature of caregiver burden during transition from hospital to home have potential implications for brain injury rehabilitation especially if results are supported in future studies. The highest levels of symptoms of depression, anxiety, stress, and strain were present during the pre-discharge period. This is understandable as caregivers are facing a new role with uncertain expectations, and earmarks the immediate pre-discharge phase as one for additional family support and intervention to minimise distress. Irrespective of the apparent improvement in coping initially experienced at 1-month following discharge, the results suggests that ongoing monitoring and support is required at least up until 3 months post-discharge to identify and assist the sizeable proportion of caregivers who experience distress at clinical levels during the transition phase.

Although the present study provides important preliminary findings in to emotional adjustment and caregiver burden during the first three months post-discharge, there are several limitations to the current study that require acknowledgment. First, small sample size and multiple comparisons may impact the level of power and Type 1 error rate. In order to minimise the impact of these statistical issues, effect sizes have been reported and interpreted in the analyses. In addition, it was beyond the scope of the current study to examine all potentially relevant factors that may be associated with caregiver emotional adjustment and perceived burden. For example, the study demonstrated that although a proportion of caregivers experienced clinically significant levels of burden, a significant number of caregivers did not. Thus, examination of the coping

mechanisms utilised by caregivers at different time points during the transitional period is recommended to inform the development of suitable support services for caregivers of people with brain injury. In addition, the degree of caregiving (e.g., practical, physical, or emotional support required) provided to the patient by the caregiver was not examined within the current study. Differences in the caregiver role may impact upon emotional adjustment and perceived burden. Thus, greater clarification regarding caregiver role is recommended for future research. Furthermore, although this study allowed for subjective response on standardised measures, it did not allow for qualitative responses. Future research could undertake a qualitative study to examine subjective views on what factors triggered their feelings of depression, anxiety, stress, and strain. Finally, previous research identified a relationship between changes in cognition and increased caregiver burden (van den Heuvel., 2001) which the present study lacked resources to measure. Further examination of the relationship of changes in cognition, behaviour, communication and personality to caregiver burden is required in the transitional period with larger samples of participants.

Conclusion

This research examined caregiver burden in the initial transition from hospital to home after rehabilitation for TBI, as previously identified as a gap in the caregiver literature (Turner et al., 2008). Previous research has examined caregiver burden in caregivers of individuals with TBI within the first year post-discharge and there has been relatively little research during the initial transition phase from hospital to home. The current research also examined a younger patient population than previously. Results showed that caregivers experience a higher prevalence of caregiver burden than the general population. Levels of burden were variable over time, tending to decrease from the first month post discharge, with the highest levels of burden (including depression, anxiety, stress, and strain) evident at pre-discharge. The longitudinal design of the study allowed for a comprehensive view of caregiver experiences, contributing to our understanding of how caregivers adjust during the transition from hospital to home. Results of this study are important for practitioners, suggesting that more specific caregiver support services and intervention strategies may be beneficial before patient discharge from hospital and during the initial period following discharge.

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Endnotes

- 1 Mean and standard deviation for caregiver age calculated from $n = 27$ due to missing data.
- 2 Effect sizes (Cohen's d) for independent samples t tests were calculated using the ClinTools Effect Size Generator — Professional Edition Version 4.1 (Devilly, 2007).
- 3 Consistent with prior research (Cope, Cole, Hali & Barkan, 1991) low disability was considered to encompass DRS scores indicative of partial disability or less (i.e., $DRS \leq 3$). High disability scores were deemed to include scores indicative of moderate disability and above (i.e., $DRS \geq 4$) (Rappaport, et al., 1982).

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