

Differential pathways of psychological distress in spouses vs. parents of people with severe traumatic brain injury (TBI): Multi-group analysis

MALCOLM I. ANDERSON¹, GRAHAME K. SIMPSON², PETER J. MOREY³,
MAGDALENA M. C. MOK⁴, TAMERA J. GOSLING¹, & LAUREN E. GILLETT²

¹Faculty of Nursing and Health, Avondale College (Sydney Campus), Wahroonga, NSW, Australia, ²Brain Injury Unit, Liverpool Health Service, Liverpool, NSW, Australia, ³Faculty of Business and Information Technology, Avondale College (Lake Macquarie Campus), Cooranbong, NSW, Australia, and ⁴Centre for Assessment Research and Development, The Hong Kong Institute of Education, New Territories, Hong Kong
(Received 12 March 2009; revised 30 August 2009; accepted 1 September 2009)

Abstract

Primary objective: A contemporary model of psychological stress based on an amalgamation of Conservation of Resources theory and the McMaster Model of Family Functioning was devised to compare the effects of neurobehavioural impairments on family functioning and psychological distress in spouses and parents caring for relatives with TBI. **Method:** Participants were 64 spouses and 58 parents. They completed the Neurobehavioral Problem Checklist, Family Assessment Device and the Brief Symptom Inventory. Structural equation modelling (SEM) was used to test the model for the combined (spouses and parents) sample. Multi-group analysis was then employed for examining differences in structural weights for spouses and parents.

Main results: SEM supported the model for the combined sample. Multi-group analysis showed for spouses cognitive and behavioural impairments significantly disrupted family functioning, which in turn increased psychological distress. In contrast, cognitive and behavioural impairments did not significantly disrupt family functioning in parents. For parents, however, cognitive impairments increased psychological distress. Furthermore, parents who reported disrupted family functioning also experienced higher levels of psychological distress. The effect of cognitive impairments was statistically more influential on the level of distress in parents when compared to spouses.

Conclusions: Understanding these differences can assist in better targeting family support interventions.

Keywords: Family, neurobehavioral, psychological, stress, traumatic brain injury.

Introduction

For the past three decades, substantial research attention has documented the impact of TBI on family members. Many studies have examined family members as a single group, aggregating parents, spouses, siblings, adult children and other relatives into one sample. However, the primary conduits of family support have been the parents or spouse of the person with TBI [1]. Researchers have therefore been concerned to ascertain and compare the impact of TBI on these family members in particular. Since the early study of Panting and Merry [2], over 30 studies have examined or reported on this issue.

A predominant concern in this research has been to determine the level of ongoing psychological and psychosocial adjustment parents and spouses have made. Elevated levels of affective distress (depression [3–7], anxiety [5, 8, 9], stress [10–12], perceived burden of care [3, 13, 14], unwelcome role changes [10], instrumental difficulties [15, 16] and increased health-seeking behaviour [10, 15]) have been documented among family members as a whole. Although early clinical descriptions suggested that

spouses were more at risk than parents [2, 17–19], subsequent research using standardized measures have not reached a consensus on this issue, with similar numbers of studies either supporting these early findings or, alternatively, finding no difference in the degree of spouse vs. parent distress. No studies have suggested that parents have elevated levels of distress in comparison to spouses.

Brooks et al. [13] and Linn et al. [20] suggested that aside from the quantitative dimension of distress, it was important to investigate whether there were qualitative differences between spouses and parents in the causes of distress. Based on the TBI family literature, qualitative differences could exist in the pattern of initial stressors reported by spouses vs. parents arising from the neurobehavioural impairments displayed by the person with TBI. Alternatively, the qualitative differences may be present in the factors that mediate the impact of those stressors on relative distress.

Few investigations have examined which aspects of the neurobehavioural profile of people with TBI (cognition, behaviour, physical) impact most strongly on the distress experienced by spouses vs. parents. In

the broader family literature, studies have found that behavioural impairments generally had a greater impact than cognitive or physical impairments on relative distress and that cognitive impairments had a greater impact than physical impairments [13, 21–23]. Three studies that did investigate whether there was a differential impact on parents vs. spouses found no differences in their subjective reports of neurobehavioural symptoms displayed by the person with TBI [4, 7, 17]. In contrast, Serio et al. [24] found that behavioural impairments had the strongest association to the unmet needs of spouses, whereas amotivation had the greater impact on parents.

Turning to mediating factors, various demographic and psychological variables have been identified as mediators of the relationship between the neurobehavioural stressors and the degree of relative distress. These have included pre-morbid social and emotional health [25], ethnicity [26], ineffective coping [4, 27, 28], the presence of unmet needs [8, 24] and perceived adequacy of social support [29–32]. The perception of social support has proved to be one of the key mediating factors. In the health literature more generally, social support has been found to moderate the impact of stress across a broad range of life situations [33]. In the TBI studies that compared parents and spouses on this variable, social support has been measured by various instruments including the Arizona Social Support interview [10], selected items from the Social Support Questionnaire [4] and the Interpersonal Support Evaluation list [34]. In two of these studies, parents reported higher levels of perceived social support than spouses [10, 34].

Interestingly, although these social support measures tap into perceived support from other family members as well as friends and work colleagues, the role of the family system as a source of social support and mediator of individual relative distress has rarely been examined. This reflects concerns [5, 35] that too much family research has focused on single caregivers in isolation of the interaction that exists between individual family members and the broader family system. Two studies have incorporated family functioning into a model of relative distress. Employing Structural Equation Modelling (SEM), Whinstanley et al. [8] found no significant pathways between the health of family functioning and a latent distress variable. In contrast, Ponsford et al. [7] conducted a series of regression analyses and found that Family Assessment Device–General Functioning was a significant correlate of elevated depression and anxiety in caregivers. However, both these studies comprised an aggregated sample of family members.

In seeking to test complex models of family functioning, SEM is a useful analytic technique. It enables the direct and indirect effects of variables to be analysed simultaneously [36]. In the first study to use SEM to investigate family adaptation to TBI, Chwalisz [37] tested a theoretical model of caregiver stress derived from the broader stressappraisal- coping theory

[38]. In this study, mental and physical health outcomes for spouses whose partners had sustained a TBI were posited as being associated with their degree of self-reported stress. The level of perceived stress was hypothesized as arising from the interaction between caregiver characteristics (age, gender, prior mental health history and appraisal of the degree of change in their partner with TBI) as mediated by the spouses' coping style and degree of social support. The study found that coping and level of social support were associated with the degree of stress reported by spouses, but did not find a significant relationship between the four caregiver characteristics and the other model variables. Chwalisz [37] observed that further investigation into the possible contribution of the neurobehavioural impairments of the person with TBI to caregiver distress was needed. Moreover, the study did not include a family systems dimension in seeking to understand the spouses' distress.

The current authors [39, 40] have previously proposed and tested a model of psychological distress using SEM. The model draws upon Hobfoll's Conservation of Resources theory (COR) [41, 42], the McMaster Model of Family Functioning [43] and Elliott and Eisdorfer's [44] normative perspective of stress. Within the model, the neurobehavioural sequelae of TBI served as chronic stressors. Furthermore, the model proposed that the family system acted as a resource, mediating the relationship between these stressors and an individual relative's psychological status. This was based on COR theory which proposes that psychological distress occurs when there is a threat or actual loss of individual or family resources [41]. Family resources were operationalized by use of the McMaster Model of Family Functioning [43], which has characteristics that are largely congruent with the conceptualizations of COR theory [39, 40, 42]. The Family Assessment Device [45] has been the most frequently used measure of family functioning in the TBI literature, employed in at least 20 studies [7, 8, 12, 21, 25, 39, 40, 46, 47].

The model was first tested on a sample of spouses [39] and subsequently on a combined sample of parents and spouses [40]. The findings in both studies supported the model. The analyses found significant pathways between the neurobehavioural impairments (as measured by the Neurobehavioral Problem Checklist (NPC) [48]) and relative distress. In addition, both studies found that the neurobehavioural impairments also had an indirect effect on relative distress through an impact upon family functioning.

Within SEM, multi-group analysis provides the capability to test for differences in pathways between sub-groups of a sample [36], namely spouses vs. parents in the current study. Multi-group analysis involved setting up an invariant model in which spouses and parents were hypothesized to have the same regression weights and a variant model in which spouses and parents were hypothesized to have different regression weights. The two models were then

directly compared using a critical ratios test as to their model fit. This analytic technique enabled one to investigate whether (i) the same pattern of neurobehavioral impairments acted as stressors on parents vs. spouses and (ii) whether family functioning played a similar mediating social support role for both groups.

Methods

Participants

The current sample included the initial 64 spouses from the first study [39] combined with a subsequent sample of 58 parents (29 couples). Ethical approval for the different components of the project was granted from the relevant New South Wales Health Area Health Service Human Research Ethics Committees. Participants were recruited from six Brain Injury Rehabilitation Units across NSW. The inclusion criteria were that the family participants (i) were living with the injured relative with TBI at the time of injury and after discharge from hospital, (ii) had primary responsibility for supporting the relative with TBI, (iii) had no pre-morbid psychiatric history and (iv) that the relative's TBI was severe (post-traumatic amnesia (PTA) greater than 24 hours or a period of coma of at least 6 hours if PTA was not known). Additional criteria were employed for the parent's group, namely that (i) they were a parental dyad, (ii) the biological parents of the person with TBI and (iii) both partners agreed to participate in the study.

The total group of relatives numbered 122. The parents of the adult child with TBI ($n=58$) were a mean age of 52 years and had been married for a mean of 27 years. Spouses ($n=64$) who had partners with TBI had a mean age of 45 years and were married for a mean of 20 years. The occupational status of the sample varied from professional and managerial positions to unskilled work, homemakers and retirees, which represents a broad range of families in terms of socio-economic background.

The relatives were the carers of 93 people with TBI, who were an average age of 34 years and a mean of 41 months post-injury (range 4–183 months). All these individuals had severe to- extremely severe brain injuries based on duration of PTA or length of coma as reported by the caregivers if PTA was not known. Reports from medical records revealed 84 injured relatives had PTA scores ranging from 2–224 days (mean \pm SD \pm 40). The remaining nine relatives with TBI were in coma for more than 6 hours (range \pm 44 days to 4 months), indicating that their injuries were also severe. The majority of injuries resulted from motor traffic accidents (70%), falls (9%), assaults (3%), sports (6%) and other (12%). Comparing the people with TBI from the two groups, there were no significant differences in gender and time post injury between the two groups based on chi-square and t-test analyses. However, results from t-test analysis ($t=43.023$; $p<0.03$) found that the duration of PTA was significantly longer

in adult children (M \pm SD \pm 45) compared to injured spouses (M \pm SD \pm 42). Although the difference was statistically significant, the mean PTA for both groups still fell into the extremely severe range.

Measures

Neurobehavioral Problem Checklist. The Neurobehavioral Problem Checklist (NPC) of the General Health and History Questionnaire [48] was utilized to measure the range of domains of neurobehavioral impairments that arise as sequels of a TBI. The NPC is a self-report questionnaire consisting of 105 items on a 4-point Likert scale that is rated from 'Never' to 'Always' by the participant. 'Does Not Apply' may be chosen if the item is not relevant to the current circumstance. The items are grouped to make up five sub-scales including: Somatic/physical, Thinking/cognition, Behaviour, Communication/language and Social. The instrument has sound psychometric properties [40, 49]. In this study the NPC scales had reliability coefficients of 0.87, 0.86, 0.94, 0.79 and 0.69, respectively, which are quite acceptable.

Family Assessment Device. The family functioning construct was operationalised using the Family Assessment Device (FAD) [45] that is based on the respected McMaster Model of Family Functioning [43] and has acceptable psychometric properties [50, 51]. The FAD is a self-report questionnaire consisting of 60 items on a 4-point Likert scale, which is rated from Strongly Agree (1) to Strongly Disagree (4). The FAD is a screening measure that consists of six scales that represent the hypothesis of the MMFF including: problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control. Additionally, a general functioning scale made up of 12 items provides a global rating of overall family functioning. Scores for unhealthy or ineffective family functioning for each scale range from 1–4, with higher scores representing ineffective family functioning. Cut-off scores for unhealthy family functioning for each scale range from 1.9–2.3. A score greater than 2 for the general functioning scale and a score of more than 2.3 for roles are considered to be in the unhealthy or ineffective range. Only scores from the general functioning and roles scales were reported in this study, which is in line with other research that has used the FAD general functioning scale as a global indicator [7, 8] or studied roles as a specific construct [52].

Brief Symptom Inventory. The psychological distress construct was operationalised by means of the Brief Symptom Inventory (BSI) [53], which is a self report questionnaire consisting of 53 items on a 5-point scale which is rated from (0) 'not at all' to (4) 'extremely'. It is designed to reflect the psychological symptoms of psychiatric, medical and nonclinical individuals from nine primary symptom dimensions and three global indices: Somatisation, depression, obsessive-

compulsive symptoms, anxiety, interpersonal sensitivity, hostility, phobic anxiety, paranoia and psychotic symptoms, global severity index, positive symptom total and positive distress index. The BSI has been well received by investigators in psychiatric, medical, non-clinical [53] and TBI populations [11, 21, 39, 40, 46, 49]. The reliability and validity of the BSI is very good and has been extensively reported [49]. There are two criteria for making a diagnosis for caseness including (a) a global severity index T-score (non-patient norms) of 63 or more or (b) a T-score (non-patient norms) of any two dimensions equal to or greater than 63. This study only assessed the depression, anxiety and hostility sub-scales in this study as BSI sub-scales such as psychoticism, obsessive compulsive and paranoid ideation may not be direct indicators of psychopathology in this population [11, 46].

Procedures

Health professionals from the six participating units reviewed their active client lists to identify participants who met the inclusion criteria and then contacted potential participants to obtain their permission to be interviewed. Each participant received an information letter, explaining the project and a consent form.

Informed consent was granted by a total of 122 participants, with only 16 people (11.6%; 16/138) refusing to take part. An investigator from the research team then made contact to set a date for the interviews with the uninjured spouses and parents. The interviews took place either at the participant’s home or at the respective rehabilitation facility of the person with TBI. For the parental dyads, each parent completed the NPC, FAD and BSI independently.

Statistical analysis

Scores from spouses and both parents were entered into SPSS version 15.0. Descriptive statistics were generated for all key variables. Inspection found that the variables were normally distributed and, therefore, parametric statistical procedures were used. t-tests were conducted to ascertain whether there were significant between-groups (parents vs. spouses) differences on the variables generated from the NPC, FAD and BSI. For these analyses, a Bonferroni correction was applied to the significance level (0.05/10, \approx 0.005) to control for Type 1 error arising from multiple comparisons.

SEM was used as a technique that allowed the

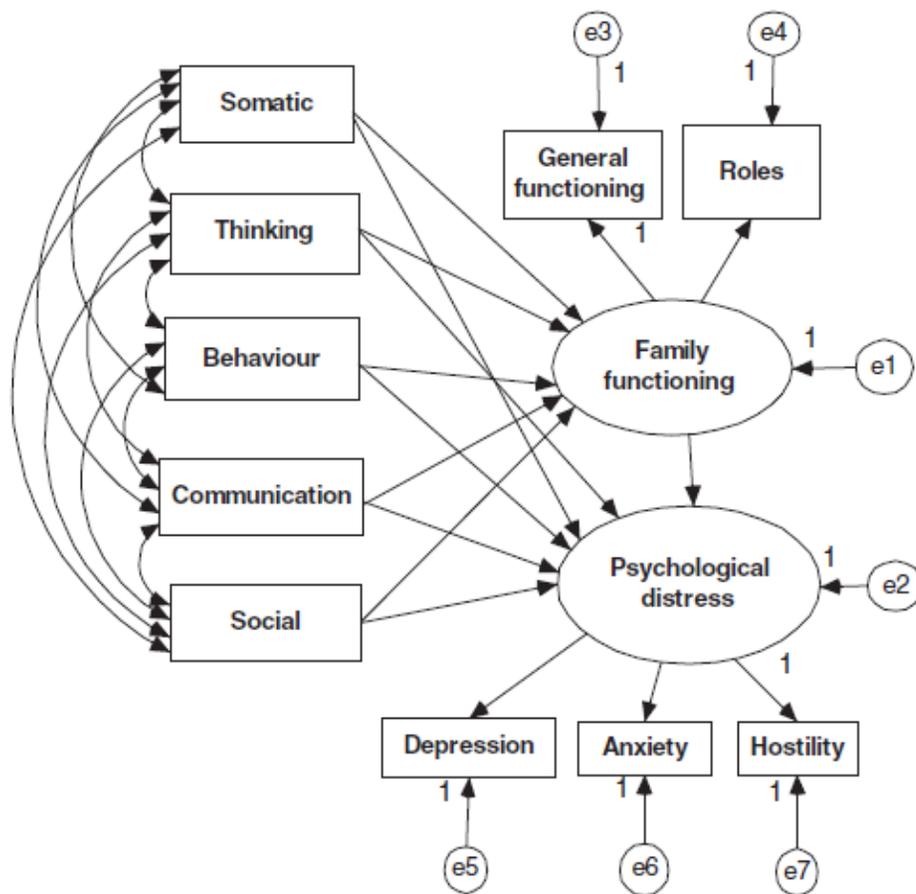


Figure 2. Initial path model of psychological distress in relatives of family members with TBI.

analysis of relationships between exogenous (explanatory) and endogenous (dependent) variables simultaneously [36]. Furthermore, it offered the ability to incorporate latent (unobserved) variables in the model, which were approximated by observed or measured variables [36]. To achieve this a four step approach was adopted to examine the relationships between the constructs neurobehavioral impairments, family functioning and psychological distress. First, using AMOS 7 software [54], a partial hybrid model (Figure 2) was constructed with a combination of latent (i.e. unobserved) and observed (i.e. measured) variables. The model comprised five observed explanatory variables including somatic, thinking (cognition), behaviour, communication and social impairments. Family functioning and psychological distress were represented as latent variables that were measured by multiple observed variables. That is, the two observed variables general functioning and roles measured the latent mediating variable family functioning. The latent variable psychological distress was measured by three observed variables including depression, anxiety and hostility. Psychological distress was also the endogenous variable in the model. Notably, this model was more extensive than the initial research [39], which was composed of a path model that specified the structural relations amongst observed variables only, with single global scales for measuring family functioning and psychological distress. In a second step maximum likelihood estimates for the model parameters using the covariance matrices for the total sample ($n=122$) were calculated [54]. The sample size was acceptable as it was within the suggested minimum range of 100–200 subjects for SEM [55–57]. Multiple measures were used to assess the fit of the data to the model namely; chi square (χ^2) statistic, RMSEA and

base line comparisons fit indices of NFI, RFI, IFI, TLI and CFI. Once a model with adequate fit was obtained, it was used as a foundation to apply multi-group analysis (step 3) to test for differences between spouses and parents. To do this, an invariant and variant model were set up, which were directly compared as to their model fit. The AIC measure was employed to determine which competing model was more parsimonious and better fitting. In the fourth step the critical ratio test was engaged to test for kinship differences in the regression weights [36].

Results

Univariate analyses

Results of t-tests conducted to ascertain whether there were any between-groups differences (spouses vs. parents) on the three measures are displayed in Table I. The Thinking/cognitive impairments sub-scale of the NPC was reported to be the most problematic by the relatives as a whole, scoring above the mid-point (2) of the scale. The between groups analysis found that spouses reported significantly more cognitive and social impairments in the relative with TBI than parents.

The FAD scores for the group as a whole fell between psychiatric and medical norms [51], which are similar to findings on TBI groups from North America [46]. Upon closer inspection spouses exceeded the mean cut-off scores for unhealthy role functioning and general functioning. Nearly two thirds of the spouses had scores in the unhealthy range for general functioning (64%) and roles (64%), which were remarkably similar to the findings reported by Camplair [49]. In contrast, general functioning and role performance for parents were in the effective range, which was consistent with non-patient norms [57] and

Table I. NPC, FAD and BSI scores for relatives of family members with TBI.

	Total group <i>M</i> (<i>SD</i>) (<i>n</i> = 122)	Spouses <i>M</i> (<i>SD</i>) (<i>n</i> = 64)	Parents <i>M</i> (<i>SD</i>) (<i>n</i> = 58)	<i>t</i> statistic*
NPC Somatic	1.82 (0.44)	1.91 (0.042)	1.71 (0.44)	ns
Thinking	2.05 (0.56)	2.19 (0.55)	1.89 (0.58)	–2.860*
Behaviour	1.93 (0.54)	2.04 (0.53)	1.81 (0.53)	ns
Communication	1.80 (0.58)	1.85 (0.62)	1.74 (0.53)	ns
Social	1.85 (0.58)	2.01 (0.58)	1.67 (0.54)	–3.280*
FAD Roles	2.28 (0.41)	2.34 (0.42)	2.21 (0.38)	ns
General functioning	2.01 (0.51)	2.16 (0.47)	1.83 (0.51)	–3.726*
BSI Depression	58.72 (10.80)	60.73 (10.1)	56.50 (11.2)	ns
Anxiety	56.19 (11.70)	57.39 (11.2)	54.86 (12.18)	ns
Hostility	57.02 (11.29)	59.58 (10.6)	54.21 (11.39)	ns

NPC = Neurobehavioral Problem Checklist; FAD = Family Assessment Device; BSI = Brief Symptom Inventory.
*Significant at Bonferroni adjusted $p = 0.005$.

other TBI families [7]. Nevertheless, half of the parents reported difficulties with role functioning and 42% reported ineffective family functioning on the general functioning scale. The t-tests found that spouses experienced significantly more difficulties with general functioning than parents, unlike previous research [7, 46].

The group mean BSI scores for relatives exceeded the means for non-patients (T1450) for depression, anxiety and hostility, which indicated that the caregivers experienced a broad range of symptoms of psychological distress. Higher percentages of spouses reported psychological distress at caseness level than parents for depression (50% vs. 35%) anxiety (36% vs. 29%) and hostility (39% vs. 26%), respectively; however, t-tests indicated that the differences on the sub-scale scores were not significant.

Model of psychological distress:

Total group First, the data for the aggregated group was screened using descriptive and correlation techniques to determine the most suitable variables to be included in the model for testing. Correlations among the 10 variables of the matrix were positive and ranged from

0.23–0.75, with 45% of the correlations above 0.50. Scores obtained on the FAD general functioning scale had correlations with the NPC variables somatic, communication and social impairments that were less than 0.30 and the FAD roles scale had a correlation with the NPC variable social, which was less than 0.3 as well. Subsequently, these weaker correlations were not included in the path model for analysis.

Then the model was submitted for analysis [54], making use of the techniques developed by Jöreskog and Sörbom [58], which was theory driven and empirically validated. An optimal model was derived using this approach by an iterative process of inspection between statistical significance of path coefficients and theoretical relevance of constructs in the model. The plausible explanatory factors somatic and communication were not statistically significant (at the 0.05 level) to be retained in the model. The model (Figure 3) for the aggregated sample comprised two explanatory observed variables, namely thinking and behaviour, which revealed significant, direct effects on the latent variable family functioning. Further, the three explanatory variables thinking and social and the latent variable Family functioning had significant direct effects on the latent variable Psychological distress. Together, these variables explained 62% of the variance

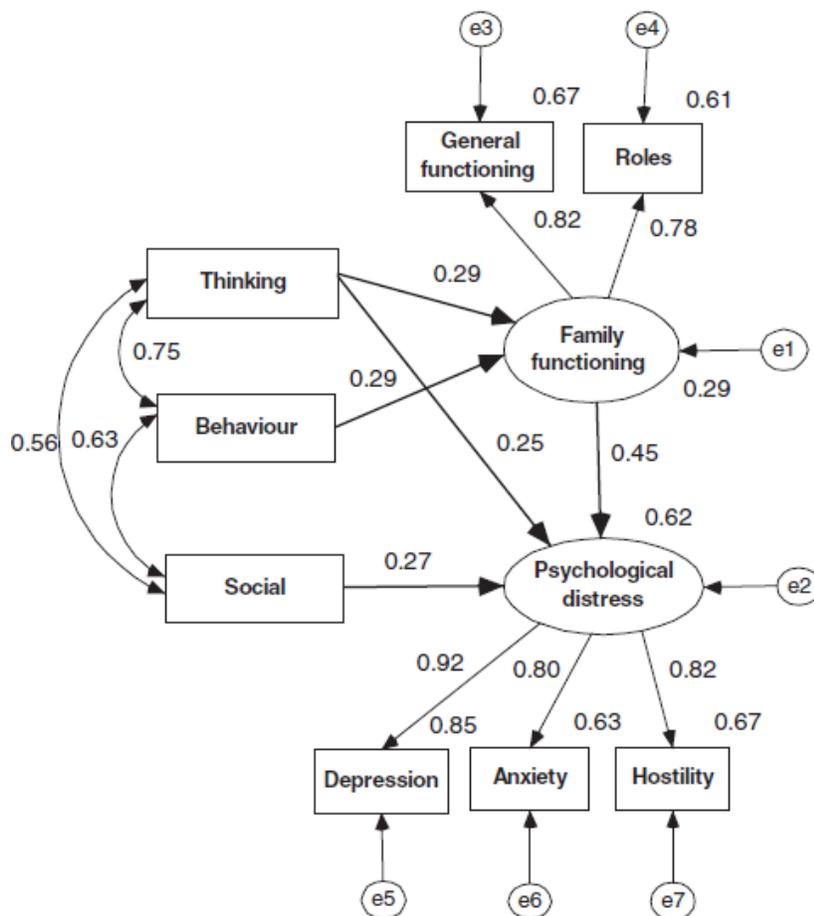


Figure 3. Path model of psychological distress in relatives of family members with TBI.

of psychological distress in relatives.

The model as a whole fitted the data very well, as indicated by the goodness-of-fit indices ($\chi^2=19.252$; $p=0.203$; NFI=0.966, RFI=0.937; IFI=0.992;

TLI=0.985, CFI=0.992 and RMSEA=0.048). The base line comparisons fit indices were all above 0.9, which constituted a good fit [59, 60]. Moreover, the RMSEA value was less than 0.05, which indicated a close fit between the data and the model [61]. Using these criteria, there was strong empirical evidence to support the hypothesized theoretical model.

Multi-group analysis was conducted comparing the fit of the group-variant model and the group invariant model and assess differences between spouses and parents in the strength of the paths between neurobehavioral impairments, family functioning and psychological distress. For both group-variant and group-invariant models a good fitting model of the relationship between neurobehavioral impairment of those with TBI and family functioning and psychological distress in caregivers who were relatives was achieved (group-variant $\chi^2=35.85$; $df=33$; $p=0.34$; group-invariant $\chi^2=46.31$; $df=38$; $p=0.167$). The baseline comparison fit indices NFI, RFI, IFI, TLI and CFI for both models were close to or are above 0.90

(range: 0.886–0.995), which also indicated the fit of the models was sufficient. Furthermore, the RMSEA yielded values for the group-variant and group-invariant path models of 0.027 and 0.043, respectively, which also demonstrated the fit of the two models was very good [62].

When the models were compared using the AIC measure [63], which takes into account both model parsimony and model fit, the score for the group variant model (113.854) was lower than the group invariant model (114.308). This indicated the group-variant model was both more parsimonious and better fitting than the group-invariant model. Subsequently, the group-variant model's estimates were used rather than the group-invariant model's estimates [36]. Based on this recommendation the group variant model, which indicated spouses and parents have one or more path coefficients that were different, was adopted for this analysis.

Model of psychological distress experienced by caregivers: Spouses

The model for psychological distress in spouses of partners with TBI, including standardized path

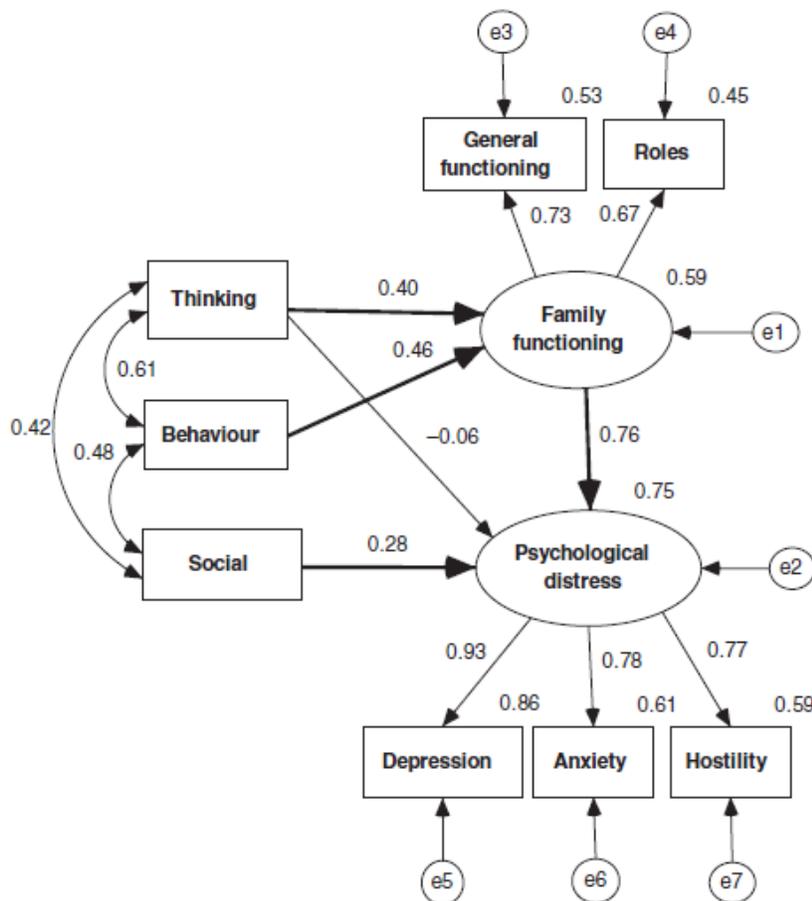


Figure 4. Model of psychological distress in spouses of partners with TBI.

coefficients, is presented in Figure 4. Parameters reaching statistical significance included the two explanatory variables thinking ($p < 0.01$) and behaviour ($p < 0.01$), which had significant direct effects on family functioning, while two explanatory variables had significant effects on psychological distress, namely social ($p < 0.01$) and the mediating variable family functioning ($p < 0.01$). Together, the variables thinking, behaviour, social and family functioning explained 75% of the variance of psychological distress in spouses, which indicated the model was a very good approximation of those factors that contribute to psychological distress in spouses of partners with TBI.

Direct and indirect effects: Spouses

Based on standardized estimates (β 's) the variable thinking had a considerable direct effect on family functioning ($\beta = 0.397$), which suggested spouses who had partners with many cognitive impairments were likely to report high levels of ineffective or unhealthy family functioning. Furthermore, as behavioural impairments increased spouses reported more ineffective family functioning ($\beta = 0.461$), which was expected. As hypothesized, spouses who reported high levels of ineffective family functioning also reported many symptoms of psychological distress ($\beta = 0.758$); which was the strongest direct path coefficient in the

model. Additionally, social impairments had a direct effect on psychological distress ($\beta = 0.284$), which suggested spouses who had partners with many social impairments experienced high levels of psychological distress.

Indirect effects were also examined to determine the influence of neurobehavioral impairments through family functioning on psychological distress. Both thinking impairments ($\beta = 0.301$) and behavioural impairments ($\beta = 0.350$) had a considerable indirect influence on psychological distress. These findings suggested cognitive and behavioural impairments disrupted family functioning and subsequently increased the level of psychological distress in spouses of partners with TBI, which was expected.

Psychological distress accounts for 86%, 61% and 59% of the variance of depression, anxiety and hostility, respectively; indicating respective reliabilities of at least 0.86, 0.61 and 0.59. Further, family functioning accounts for 53% and 45% of the variance in general functioning and roles; indicating respective reliabilities of 0.53 and 0.45.

Model of psychological distress experienced by caregivers: Parents

In the parent model (Figure 5) parameters reaching statistical significance comprised two plausible

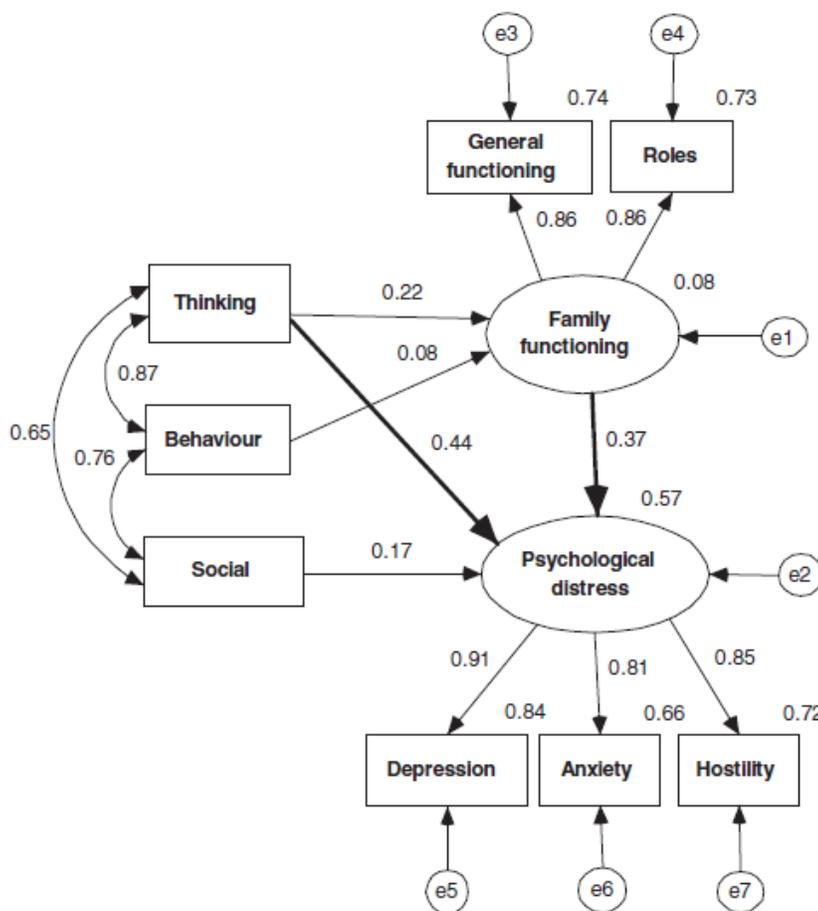


Figure 5. Model of psychological distress in parents of adult children with TBI.

explanatory variables, namely thinking for the level of psychological distress ($p < 0.01$) and family functioning for the level of psychological distress ($p < 0.01$). Jointly, thinking and family functioning explained 57% of the variance of psychological distress in parents, which indicated the model was a sound approximation of those factors that contribute to psychological distress. Nevertheless, thinking and behaviour had no significant influence on family functioning, with only 8% of the variance in family functioning explained by these variables, which suggested other factors might be influencing family dynamics where parents were caring for adult children with TBI.

Direct and indirect effects: Parents

The variable thinking had a considerable direct effect on psychological distress ($p = 0.436$), which suggested parents of adult children with many cognitive impairments were likely to report high level of psychological distress. Furthermore, parents who reported high levels of ineffective family functioning also reported many symptoms of psychological distress ($p = 0.372$), which was expected. On the other hand, the neurobehavioral impairment constructs had no significant direct effect on family functioning or subsequent indirect effect on psychological distress in the model, which was unexpected. Psychological distress accounts for 84%, 66% and 85% of the variance of depression, anxiety and hostility, respectively; indicating respective reliabilities of at least 0.84, 0.66 and 0.85. Furthermore, family functioning accounts for 74% and 73% of the variance in general functioning and roles; indicating respective reliabilities of 0.74 and 0.73.

Spouse vs. parent

For both spouses and parents, family functioning had a direct influence on psychological distress. For parents only, more cognitive impairments led to more symptoms of psychological distress. On the other hand, more cognitive and behavioural impairments reported by spouses resulted in high levels of ineffective family functioning and subsequent psychological distress. For spouses only, more social impairments led to an increase in symptoms of psychological distress.

In order to determine the differences between path coefficients for spouses and parents the critical ratios for differences test was applied (Step 4). The path coefficient between thinking and psychological distress was the only path coefficient that was significantly different (critical ratio difference = 2.288) between the groups. For parents, the association between thinking and psychological distress was significant but not for spouses. This means thinking or cognitive impairments in the adult child with TBI were more influential on the level of psychological distress in parents when compared to spouses of partners with TBI.

Discussion

This study tested a contemporary model of stress based on COR theory [41, 42] and the McMaster Model of Family Functioning [43] employing multigroup analysis. Overall, the model performed strongly, accounting for a substantial proportion of the variance in relative distress for the aggregated sample as a whole (step 2). Moreover, the initial analysis indicated that different interactional patterns for spouses vs. parents existed among the three sets of variables (i.e. a variant model). The next step of analysis generated these unique models for parents and spouses (step 3, displayed in Figures 4 and 5). Finally, employing a critical ratios test, the pathways in the two models were tested against each other, identifying that the association between cognition and relative distress for parents distinguished between the two models.

The association between cognitive impairments and distress for the parents identified a differential impact in the pattern of neurobehavioral impairments upon parents vs. spouses. Previous research has reported the contribution of cognitive impairments to relatives including parental distress [7, 21]. Interestingly, the descriptive statistics indicated that the parents did not identify as high a level of cognitive impairment as the spouses. Despite this, the strong direct pathway between cognition and distress was not found in the spouses group. There are at least two possible explanations for this association among parents. First, the distress could be associated with the demands of managing a person with memory, attentional or executive impairments [21]. Another possibility arises from findings in previous studies that parents are more concerned about the future care needs of the person with TBI than spouses [4, 20]. The cognitive impairments displayed by their adult child may be an ongoing reminder of the ever-present problem of ‘Who will care for my child when I am no longer able to do so?’.

The models generated at step 3 accounted for a significant proportion of the variance in distress for the spouses and the parents. In terms of the impact of neurobehavioral impairments, the spouse’s model displayed an association between cognitive, behavioural and social impairments and family functioning or psychological distress. However, as reported in previous studies [7, 21], neither physical (somatic) nor communication impairments had a negative association with disrupted family functioning or relative distress.

Furthermore, in the spouses group, the family unit was vulnerable to the impact of high levels of behavioural and cognitive impairments (a direct effect). Marital dyads typically form the primary structure within family units and, therefore, when a partner is injured there is significant potential for disruption to family functioning overall [17, 64]. This was reflected in the descriptive statistics, with the spouses’ mean scores for general functioning and roles above the cut-off scores for disrupted family functioning and nearly

two thirds of the sample falling in the unhealthy range. It was this disruption, a diminishing of social support, which in turn linked the neurobehavioral impairments to increased levels of psychological distress (indirect effect). This reflects findings from a previous study using SEM on an aggregated sample of parents and spouses, which also found that neurobehavioral impairments did not have a direct effect on relative distress, but an indirect effect mediated through the disruption to family functioning [8].

In the model for the parents, neurobehavioral impairments were not associated with disrupted family functioning. One reason could be that the preserved parental dyads mitigated the extent of the negative impact of the TBI on the family system as a whole.

However, it may also be that the presence of another uninjured adult within the family setting (viz. the second parent) helped to balance general family functioning. Moreover, the recruitment of this particular sub-sample of parents may account for the difference between the two-groups of relatives in the univariate analyses. The finding contrasts with all previous studies, none of which found a significant difference between spouses and parents on the full FAD [7, 21] or general functioning sub-scale [36, 65]. If a broader range of parents had been recruited, including parents who were single, separated, divorced and widowed or a parent who had remarried so that a step-parent was also involved in providing care, the results may have been different. Nevertheless, despite their relationships remaining intact, parents were not emotionally immune to the consequences of TBI, with about a third of parents presenting with clinically elevated scores for anxiety, depression and hostility.

Clinical implications

A number of clinical implications arise from these findings. It highlights again the potential role that spouse support groups could play [66]. Moreover; interventions focused on restoring the family relationships may alleviate individual relative distress. Programmes that provide family/relationship counselling [67] or training for spouses in the knowledge and skills to manage and minimize the impact of behavioural and cognitive impairments [68] may be a useful adjunct to the provision of counselling for depression or anxiety. Limitations and directions for future studies There are some limitations to be considered when taking into account the findings of this investigation. The findings in this study are based on families who remained together following rehabilitation and well into the future, which suggests these families may have made some degree of adjustment, compared to those families that have chosen to disengage. Moreover, a control group is needed to identify the extent caregivers of relatives with TBI differ from families supporting people who sustained other types of trauma, chronic illness or disability. The model was not exhaustive in testing all possible types of mediating

variables. Other variables that might also influence the link between neurobehavioral impairments and psychological distress include coping skills [37], physical health status [69], the degree of psychosocial integration of the person with TBI [8], the level of family empowerment [70, 71] and the degree of perceived social support from a broader range of sources. The current findings should be replicated taking into account these important additional variables. The generalisability of the findings was limited by certain characteristics of the sample. The mean age of the non-injured spouses (45 years) and duration of the marriages (average 20 years) were greater than in many studies and therefore the findings may not apply to younger couples married over shorter time periods. Finally, the caregivers in this study were Caucasian from English speaking backgrounds. Sander et al. [26] have reported that family support arrangements do vary depending on culture. Therefore, additional research is needed to replicate the current findings with people from various cultural backgrounds.

Conclusion

Given the complex interactions between multiple variables that characterize the experience of families, the findings from this study can be considered to be among the first in the TBI literature to employ SEM to identify critical pathways and relationships in family stress and adaptation. Results from this research confirm the hypothesized model, namely that neurobehavioral impairments had both direct and indirect (mediated by the disruption caused by family functioning) effects on relative distress. More particularly, employing a more sophisticated SEM, namely multi-group analysis, the results confirmed that there were different pathways associated with the distress experienced by spouses in contrast to the parents, which can assist in better targeting of family support interventions.

Acknowledgements

This work was supported by the Avondale College Foundation and the Australasian Research Institute (Grant 050301). The researchers acknowledge the contributions made by the staff from the Brain Injury Rehabilitation Programmes in NSW in facilitating this project.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

1. Perlez A, Kinsella G, Crowe S. Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology* 1999;44:6–35.
 2. Panting A, Merry PH. The long-term rehabilitation of severe head injuries with particular reference to the need of social and medical support for the patients family. *Rehabilitation* 1972;28:33–37.
 3. Rivera P, Elliott TR, Berry JW, Grant JS, Oswald K. Predictors of caregiver depression among communityresiding families living with traumatic brain injury. *NeuroRehabilitation* 2007;22:3–8.
 4. Knight RG, Devereux RT, Godfrey HPD. Caring for a family member with a traumatic brain injury. *Brain Injury* 1998;12: 467–481.
 5. Perlesz A, Kinsella G, Crowe S. Psychological distress and family satisfaction following traumatic brain injury: Injured individuals and their primary, secondary, and tertiary carers. *Journal of Head Trauma Rehabilitation* 2000;15:909–929.
 6. Gillen R, Tennen H, Affleck G, Steinpreis R. Distress, depressive symptoms, and depressive disorder among care givers of patients with brain injury. *Journal of Head Trauma Rehabilitation* 1998;13:31–43.
 7. Ponsford J, Olver J, Ponsford M, Nelms R. Long term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Injury* 2003;17:453–468.
 8. Winstanly J, Simpson GK, Tate RL, Miles B. Early indicators and causal factors of psychological distress in relatives during rehabilitation following severe TBI: Findings from the Brain Injury Outcomes Study. *Journal of Head Trauma Rehabilitation* 2006;21:453–466.
 9. Livingston MG, Brooks DN, Bond MR. Patient outcome in the year following severe head injury and relatives' psychiatric and social functioning. *Journal of Neurology, Neurosurgery, and Psychiatry* 1985a;48:876–881.
 10. Leatham J, Heath E, Woolley C. Relatives perceptions of role change, social support and stress after traumatic brain injury. *Brain Injury* 1996;10:543–546.
 11. Gervasio AH, Kreutzer JS. Kinship and family members' psychological distress after traumatic brain injury: A large sample study. *Journal of Head Trauma Rehabilitation* 1997;12:14–26.
 12. Groom KM, Shaw TG, O'Connor ME, Howard NI, Pickens A. Neurobehavioural symptoms and family functioning in traumatically brain injured adults. *Archives of Clinical Neuropsychology* 1998;13:695–711.
 13. Brooks N, Campsie L, Symington C, Beatie A, McKinlay W. The effects of severe head injury on patient and relative within seven years of injury. *Journal of Head Trauma Rehabilitation* 1987;2:1–13.
 14. Hoofien D, Gilboa A, Vakil E, Donovik P. Traumatic brain injury (TBI) 10–20 years later: A comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury* 2001;15:189–209.
 15. Hall KM, Karzmark P, Stevens M, Englander J, O'Hare P, Wright J. Family stressors in traumatic brain injury: A twoyear follow-up. *Archives of Physical Medicine and Rehabilitation* 1994;75:876–884.
 16. Wells R, Dywan J, Dumas J. Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury* 2005;19: 1105–1115.
 17. Lezak M. Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology* 1988;10:111–123.
 18. Thomsen IV. The patient with severe head injury and his family. *Scandinavian Journal of Rehabilitation Medicine* 1974;6:180–183.
 19. Thomsen IV. Late outcome of very severe blunt head trauma: A 10–15 year follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry* 1984;47:260–268.
 20. Linn RT, Allen K, Willer BS. Affective symptoms in the chronic stage of traumatic brain injury: A study of married couples. *Brain Injury* 1993;8:135–147.
 21. Kreutzer JS, Gervasio AH, Camplair PS. Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury* 1994;8:211–230.
 22. Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury* 1998;12:225–238.
 23. Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden during the year following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology* 2002;24:434–447.
 24. Serio CD, Kreutzer JS, Gervasio AH. Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation* 1995;10:32–45.
 25. Sander AM, Sher M, Malec JF, High Jr WM, Thompson RN, Moessner AM, Josey J. Preinjury emotional and family functioning in caregivers of persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* 2003;84:197–203.
 26. Sander AM, Davis LC, Struchen MA, Atchison T, Sherer M, Malec JF, Nakase-Richardson R. Relationship of race/ ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *NeuroRehabilitation* 2007;22:9–17.
 27. Flanagan DAJ. A retrospective analysis of expressed emotion (EE) and affective distress in a sample of relatives caring for traumatically brain-injured (TBI) family members. *British Journal of Clinical Psychology* 1998;37:431–439.
 28. Stebbins P, Pakenham KI. Irrational schematic beliefs and psychological distress in caregivers of people with severe traumatic brain injury. *Rehabilitation Psychology* 2001;46: 178–194.
 29. Sander AM, High Jr WM, Hanny HJ, Sherer M. Predictors of psychological health in caregivers of patients with closed head injury. *Brain Injury* 1997;11:235–249.
 30. Harris JK, Godfrey HPD, Partridge FM, Knight RG. Caregiver depression following traumatic brain injury (TBI): A consequence of adverse effects on family members? *Brain Injury* 2001;15:223–238.
 31. Ergh TC, Rapport LJ, Coleman RD, Hanks RA. Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation* 2002;17:155–175.
 32. Ergh TC, Hanks RA, Rapport LJ, Coleman RD. Social support moderates caregiver life satisfaction following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology* 2003;25:1090–1101.
 33. Rice VH. *Handbook of stress and coping: Implications for nursing research, theory and practice*. Thousand Oaks, CA: Sage; 2000.
 34. Chronister J, Chan F. A stress process model of caregiving for individuals with traumatic brain injury. *Rehabilitation Psychology* 2006;51:190–201.
 35. Gan C, Schuller R. Family system outcome following acquired brain injury: Clinical and research perspectives. *Brain Injury* 2002;16:311–322.
 36. Ho R. *Handbook of univariate and multivariate data analysis and interpretation with SPSS*. Boca Raton: Chapman & Hall/CRC; 2006.
- 942 M. I. Anderson et al.
- Downloaded By: [Anderson, Malcolm I.] At: 05:23 21 October 2009
37. Chwalisz K. The perceived stress model of caregiver burden: Evidence from spouses of persons with brain injuries. *Rehabilitation Psychology* 1996;41:91–113.
 38. Lazarus R, Folkman S. Transactional theory and research on emotions and coping. *European Journal of Personality* 1987;1:141–169.
 39. Anderson MI, Parmenter TR, Mok M. The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: Path model analysis. *Brain Injury* 2002;6:743–757.
 40. Anderson MI, Simpson G, Mok MC, Parmenter TR. A contemporary model of stress for understanding family functioning and the psychological distress in relatives of people with severe traumatic brain injury (TBI). In: Johns D, editor. *Stress and its impact on society*. New York: Nova

Science Publishers; 2006. p 23–56.

41. Hobfoll SE. Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist* 1989;44: 513–524.
42. Hobfoll SE, Spielberger CD. Family stress: Integrating theory and measurement. *Journal of Family Psychology* 1992;6:99–112.
43. Epstein NB, Bishop DS, Levin S. The McMaster model of family functioning. *Journal of Marriage and Family Counseling* 1978;4:19–31.
44. Elliott GR, Eisdorfer C. *Stress and human health*. New York: Springer Publishing Company; 1982.
45. Epstein NB, Baldwin LM, Bishop DS. The McMaster family assessment device. *Journal of Marital and Family Therapy* 1983;9:171–180.
46. Kreutzer JS, Gervasio AH, Camplair PS. Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury* 1994;8:197–210.
47. Kosciulek JF. Relationship between family schema to family adaptation to brain injury. *Brain Injury* 1997;11:821–830.
48. Kreutzer J, Doherty K, Turner, H, Walland P, Leininger B. *The General Health and History Questionnaire*. Richmond, VA: Rehabilitation Research and Training Center on Severe Traumatic Brain Injury, Medical College of Virginia; 1987.
49. Camplair PS. *The impact of disability following head injury on caregivers' psychological status and family functioning [dissertation]*. Richmond, VA: Virginia Commonwealth University; 1989. 153p. Available from: UMI Dissertation Services, Ann Arbor MI; 9019593.
50. Bishop DS, Miller IW. Traumatic brain injury: Empirical family assessment techniques. *Journal of Head Trauma Rehabilitation* 1988;3:6–30.
51. Kabacoff RI, Miller IW, Bishop DS, Epstein NB, Keitner GI. A psychometric study of the McMaster family assessment device in psychiatric, medical, and nonclinical samples. *Journal of Family Psychology* 1990;3:431–439.
52. Frosch S, Gruber A, Jones C, et al. The long-term effects of traumatic brain injury on the roles of caregivers. *Brain Injury* 1997;11:891–906.
53. Derogatis LR. *Brief Symptom Inventory: Administration, scoring and procedures manual*. Minneapolis: National Computer Systems, Inc; 1993.
54. Arbuckle JL, Wothke W. *AMOS 7 [Computer software]*, Chicago: SPSS Inc; 2006.
55. Ding L, Velicer WF, Harlow LL. Effects of estimation methods, number of indicators per factor, and improper solutions on structural equation modeling fit indices. *Structural Equation Modeling* 1995;2:119–143.
56. Kline RB. *Principles and practice of structural equation modelling*. 2nd ed. New York: Guilford Press; 2005.
57. Hoyle RH. *Structural equation modeling: Concepts, issues, and applications*. Thousand Oaks, CA: Sage Publications; 1995.
58. Jöreskog KG, Sörbom D. *LISREL 8: Users reference guide*. Chicago: Scientific Software International; 1993.
59. Bentler PM. Comparative indices in structural models. *Psychological Bulletin* 1980;107:238–246.
60. Bentler PM, Bonnett DG. Significance tests for goodness of fit in the analysis of covariant structures. *Psychological Bulletin* 1980;88:588–606.
61. MacCullam RC, Hong S. Power analysis in covariance structure modeling using GFA and AGFI. *Multivariate Behavioural Research* 1997;32:193–210.
62. Browne MW, Cudeck R. Alternatives ways of assessing model fit. In: Bollen KA, Long JS, editors. *Testing structural equation models*. Newbury Park, CA: Sage; 1993. p 136–162.
63. Akaike H. Factor analysis and AIC. *Psychometrika* 1987;52: 317–332.
64. Verhaege S, Defloor T, Grypdonck M. Stress and coping among families of patients with traumatic brain injury: A review of the literature. *Journal of Clinical Nursing* 2005;14:1004–1012.
65. Tate R, Cameron ID, Whinstanley J, Myles B, Harris R. *The brain injury outcomes study-Final report 2004 June*. Rehabilitation Studies Unit, University of Sydney.
66. Zeigler EA. Reflections of a spouses' group. *Cognitive Rehabilitation* 1990;8:14–19.
67. Lørgi M. The family systems approach to treating families of persons with brain injury: A potential collaboration between family therapist and brain injury professional. *Brain Injury* 2003;17:175–187.
68. Carnevale GJ, Anselmi V, Busichio K, Millis SR. Changes in ratings of caregiver burden following a community-based behavior management program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation* 2002;17:83–95.
69. McPherson KM, McNaughton HK. Brain injury-the perceived health of carers. *Disability and Rehabilitation* 2000;22:683–689.
70. Man DKW. Family caregivers' reactions and coping for persons with brain injury. *Brain Injury* 2002;16:1025–1038.
71. Man DKW. *The empowering of Hong Kong Chinese families with a brain damaged member: Its investigation and measurement*. *Brain Injury* 1998;12:245–254.