

Chapter 2

**A CONTEMPORARY MODEL OF STRESS FOR
UNDERSTANDING FAMILY FUNCTIONING
AND THE PSYCHOLOGICAL DISTRESS IN
RELATIVES OF PEOPLE WITH SEVERE
TRAUMATIC BRAIN INJURY (TBI)**

Malcolm Anderson

Faculty of Nursing and Health, Avondale College, Sydney Adventist Hospital Campus,
Wahroonga, New South Wales, Australia

ABSTRACT

Objective

Conservation of Resources, a theory of stress and coping, was combined with the McMaster Model of Family Functioning to form a unique framework to test the relationship between neurobehavioural impairments, family functioning and psychological distress in relatives of people with severe TBI. The model proposed that chronic stressors (i.e. neurobehavioural impairments) would have both a direct effect on relative distress, as well as indirect effects as mediated by disrupted family functioning.

Method

This multi-site study used an *ex post facto* design with a sample of 104 relatives (40 parents and 64 spouses) from NSW. Measures included the Neurobehavioural problem Checklist, Brief Symptom Inventory, and Family Assessment Device. Structural equation modelling was used to test the model. In parallel, in-depth interviews based on the McMaster model (i.e. Structured Interview of Family Functioning) were conducted with a sub-group of the relatives (n=10) to more fully explore the family dynamics.

Results

Direct effects were found between all 3 components of the model: 1. Severe neurobehavioural impairments had a direct effect on relative distress; 2. Relatives reporting high levels of neurobehavioural impairments also identified significant disruption in family functioning; 3. Disrupted family functioning was associated with high levels of distress. Significantly, relative distress was intensified by the indirect effects of neurobehavioural impairments mediated by the disruption to family functioning. The interview data supported the model, but also found that neurobehavioural impairments disrupted affective relationships among family members, an issue not detected by the standardised scales.

Conclusions

There are at least two pathways by which neurobehavioural impairments impact upon relative distress, suggesting that treatment of such distress should also target the broader disruption to family functioning. A mixed method approach may strengthen the validity of research into the complex nature of family adaptation to TBI.

INTRODUCTION

New approaches to conceptualising and addressing human problems can emerge from the synthesis and application of disparate theories drawn from different academic disciplines to focus attention on the study of specific issues of interest. Hobfoll's Conservation of Resources (COR) theory (1988, 1989) has conceptualised stress as 'a reaction to the environment in which there is (a) the threat of loss of resources, (b) the net loss of resources, or (c) a lack of resource gain following the investment of resources' (p.516) and the theory has been widely applied to individuals. In particular, COR theory has been used to address psychological distress in individuals facing major life events such as medical illness and natural disasters.

Integrating a normative model of family functioning with Hobfoll's conceptualisations of stress provides a potentially strong framework for analysing family systems under stress. The McMaster Model of Family Functioning (MMFF) (Epstein, Bishop et al., 1978) is a widely accepted model for studying family functioning in medical, psychiatric and brain injury populations. The current chapter will demonstrate how a synthesis of COR and the MMFF can be applied to advance the understanding of the dynamics of relative distress when a family member sustains a traumatic brain injury (TBI). Specifically, the characteristic pattern of injury and sequelae of TBI will be briefly delineated; the literature on the nature of family distress after TBI reviewed; the analytic model developed by the authors incorporating COR and MMFF described; and the model tested with two samples of family members who have a relative with a TBI, using a mixed method approach.

The Characteristic Pattern of Injury and Sequelae of TBI

TBI occurs unexpectedly and can affect people from all walks of life from any age group. In this context, the meaning of 'traumatic' is as a technical medical descriptor for a physical injury or wound caused by external force or violence, as distinct from the psychological meaning of trauma as a term indicating emotional distress. TBI can be defined as

"an injury to the brain [from external causes] which results in deterioration in cognitive, physical, emotional or independent functioning...these impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment" (Department of Human Services and Health, 1994)

The most common causes of TBI are road traffic accidents (40%) followed by sport and recreation (25.2%), falls (20.6%), assaults (8.2%) and miscellaneous other causes (6.1%).

(Tate, McDonald, et al., 1998) The incidence of TBI in Australia is estimated at 100 per 100,000 new cases per year (Tate, McDonald, et al., 1998), comparable to rates in other Western developed nations including the United States (Thurman and Guerrero, 1999). Males sustain TBI more frequently than females, with a sex ratio of 2.7:1. The most common age group sustaining such injuries are the 15–24 year age range, among whom the incidence rate rises to 245 per 100,000, with the rate for young males within this age group peaking at 386 per 100,000.

As indicated in the definition, the impairments that arise from a TBI can be permanent and lead to varying degrees of disability and psychosocial problems. Characteristic neurobehavioural sequelae include motor-sensory, cognitive and behavioural impairments. Common motor-sensory impairments include visual problems, poor balance, incoordination, paralysis or restricted range of movement in either the arms or legs, difficulties producing intelligible speech, and changes in taste and smell. Up to 42% of people with TBI may experience one or more of these types of impairments (Olver, Ponsford et al, 1996; Tate, Broe et al, 1989). Cognitive impairments can include problems with memory, attention, speed of information processing, planning and organising, problem-solving, poor mental flexibility and communication difficulties, both in understanding what other people say and communicating to others in a way they can understand (i.e., receptive and expressive aphasia). Up to 74% of people after TBI may report one or more of these types of impairments. (McDonald, Togher et al., 1999; Ponsford, Olver et al., 1995; Tate, Fenelon et al., 1991). Finally behavioural impairments can include increased impulsivity, reduced levels of control of emotions, self-centredness, lack of insight, irritability and temper control problems, including verbal or physical aggression. Between 60% and 80% of people with TBI may have one or more of these type of impairments (Thomsen, 1984; Thomsen, 1994).

Often people with TBI will have a normal life expectancy but may be left with continuing disabilities as a result of these neurobehavioural impairments that involve profound economic, social and personal costs for decades to come. For example, rates of successful return to work among people with severe injuries at the 5-year post-injury mark are low, typically ranging between 30% - 40% (Olver et al., 1996). Many people either lose all their leisure activities or have to change activities, with up to 63% of people with TBI having to make changes to the sort of leisure activities that they pursued pre-injury (Olver et al., 1996). The rate of relationship breakdown when one partner sustains a TBI is also high, with rates

ranging between 55% and 78% (Tate et al., 1989; Thomsen, 1984). Up to half of people with TBI report that they had lost friends and become more socially isolated since the injury (Olver et al., 1996; Tate et al., 1989). Not surprisingly, people with TBI can experience a range of differing psychological reactions to the injury and consequent changes in their lives. This can include depression, anxiety, low self-esteem and thinking about suicide. Between 30% and 40% of people can experience periods of depression. Finally, almost 1 in 5 people will attempt suicide after a TBI (Simpson and Tate, 2002).

A REVIEW OF THE LITERATURE ON FAMILY DISTRESS AFTER TBI

The previous section has outlined the common neurobehavioural impairments and the vocational, social and psychological consequences that occur as the result of a TBI. However, the impact of such an injury is wider than just the individual who is injured. It is estimated that at least three to four people, usually relatives of the person with TBI, are also directly affected by the event (Levin, Benton et al., 1982). Therefore, these people are also “casualties”, and many will be profoundly affected by the changes that occur when a family member is injured.

Subsequently, the topic of psychological distress in relatives of individuals with TBI has received considerable attention over the last three decades and the data bank of information on psychological distress is growing. Four separate avenues of investigation have evolved that have assisted in understanding the effect of TBI on close relatives, and will be outlined within this section of the chapter. First, there has been a substantial body of research documenting the direct effects of the neurobehavioral impairments sustained by the person with TBI on the psychological well being of relatives. Similarly, the second avenue focused on examining the direct effect of TBI on marital and family relationships. However, much of the early research treated these areas as independent domains. The third avenue of investigation has comprised the examination of the interactions between family functioning and psychological distress in relatives, and this area has received much less research attention. Nevertheless, the studies of the impact of TBI on families within each of these approaches have been limited, by the lack of a unified theoretical approach for understanding psychological distress in relatives.

Subsequently, Anderson, Parmenter and Mok, (2002) have developed an approach to the field drawing upon a contemporary theory of stress based on COR theory (Hobfoll, 1988, 1989; Hobfoll and Spielberger, 1992) and the MMFF (Epstein, Bishop et al., 1978), within which the three previous avenues of investigation could be combined to form a multidimensional model for understanding psychological distress in spouse/caregivers of partners with TBI. As will be discussed each of these avenues has provided important insights on the consequences of TBI, with the later approach providing a possible template for researchers and clinicians to use and build upon for future treatment plans and research.

Direct Effects of Neurobehavioural Impairments on Psychological Distress Experienced by Relatives of People with TBI

A large number of studies have focused on the direct effect of neurobehavioral impairments sustained by the person with TBI on the psychological well being of relatives. The findings from these studies were generally consistent over the years with relatives reporting high levels of psychological distress and burden, which was often related to cognitive, behavioural and personality changes experienced by the person with TBI (Gervasio and Kreutzer, 1997; Gillen, Tennen et al., 1998; Hawley, Ward et al., 2003; Oddy, Humphrey et al., 1978; Linn, Allen, et al., 1993; McKinlay, Brooks et al., 1981; Brooks, Campsie et al., 1986, 1987; Kinsella, 1991; Lamont, 1993; Ponsford, Olver et al., 2003). For instance, Kinsella (1991) reported anxiety and depression amongst mothers of sons with TBI, which was closely associated with loss of "emotional control." Similarly, Ponsford et al. (2003) reported clinically significant anxiety and depression amongst caregivers, which was related to the number of cognitive, behavioural and emotional impairments of chronic TBI. Moreover, some studies have suggested that the distress and burden experienced by relatives increases rather than dissipates over the years, with Hooffien, Gilboa et al. (2001) reporting high levels of burden and distress in relatives up to 20 years post injury.

In groundbreaking research, a group of investigators from Richmond, Virginia expanded the understanding of psychological distress in caregivers by studying broader domains of psychopathology in relatives that may have been associated with stressful events such as TBI. Kreutzer and Gervasio et al. (1994a), using the Brief Symptom Inventory (BSI; Derogatis (1993) found that elevated symptoms of somatization, obsessive-compulsive, interpersonal sensitivity, paranoid ideation, psychoticism, and general distress were prevalent amongst many of the caregivers. Similar findings were reported in a second larger study (Gervasio and Kreutzer, 1997) with only a five percent difference between most of the psychological dimensions. Moreover, cognitive, behavioural, communication and social impairments of TBI were found to be associated the majority of the BSI distress subscales with behavioural impairments being the strongest predictor among these variables (Kreutzer et al., 1994b), consistent with other findings in the literature.

Effects of Neurobehavioural Impairments on Family Functioning

In parallel with the research being conducted on psychological distress, investigators also examined the effects of neurobehavioural impairments on family functioning. Researchers and clinicians realised the importance of studying the effect of TBI on marital and family relationships because the caring responsibilities rested largely with parents or spouses of the person with TBI (Knight, Devereux, et al., 1998), and these family members played a significant part in the success or otherwise of the rehabilitation and long term care of their relative. Therefore, it stood to reason that studying family outcome following TBI would assist clinicians and researchers better understand changes in family dynamics and develop treatment regimes to maximum advantage.

Initially researchers focused on role functioning and then progressively expanded their interests to explore family functioning from a multidimensional perspective. Significant changes in role functioning were found to occur with many relatives experiencing poor sexual

relations, difficulties with managing family finances, isolation from friends and acquaintances, and diminished participation in leisure activities and little or no time for vacation, which was persistent over the long term (Frosh and Gruber, 1997; Rosenbaum and Najansen, 1976; Livingston, Brooks et al., 1985b, 1985a; Leatham, Heath et al, 1996; Lezak, 1978, 1986, 1988; Marsh et al., 1998).

Furthermore, the disruption with role functioning was attributed to the intensity of neurobehavioural sequelae. For instance, in her classic clinical observations Lezak (1978) argued that "characterological" alterations created the greatest disruption in family relationships. She described behavioural, cognitive and social impairments as having the greatest impact on the family rather than physical dependency. In particular when change in personality was severe the injured person was 'dependent, demanding, irresponsible, foolish and frankly dangerous' (p. 593). More recently, Frosch and Gruber et al. (1997) found that the more behavioural impairments (aggressiveness, anxiety, egocentricity, impulsiveness, inappropriate social behaviour, irritability, mood swings, and temper outburst) manifested by the injured person the greater the number of role changes experienced in the family.

Other researchers have taken a broader perspective than focusing solely on roles, adopting instruments to assess families from a multidimensional perspective, which has provided informative but sometimes inconsistent findings on the effects of neurobehavioural impairments on the organisation, structure and transactional patterns within the family system. On the one hand, using the Family Assessment Device (Epstein Baldwin et al., 1983), some studies from North America have reported that significant proportions of families caring for relatives with TBI could be classified as having 'unhealthy' or ineffective family functioning in problem solving, communication, affective responsiveness, affective involvement, roles and behaviour control (Kreutzer et al, 1994a; Bragg, Klockers et al., 1992). High levels of family stress have also been reported using the Family Assessment Measure-111 (Gan and Schuller, 2002; Skinner, Steinhauer, and Santa-Barbara, 1995). However, other researchers using the FAD have reported that family functioning remained quite stable and was robust despite the burden of living with the disabilities associated with TBI, with families reporting levels of family functioning similar to healthy families (Hall, Karzmark et al., 1994; Ponsford, Olver et al, 2003; Boyle and Haynes, 2002). The discrepancy between these sets of findings may be related to sample bias, the level of attendant support provided to relatives and the time the families were interviewed after the injury (Ponsford, et al., 2003).

Similarly to the role-related research reported above, researchers have also investigated which neurobehavioural impairments may influence a broader set of domains of family functioning (Kreutzer, Gervasio et al., 1994b; Ponsford et al. 2003). Kreutzer et al. (1994b) did this by using a clinical rating measure, the Problem Checklist (PCL) of the General Health and History Questionnaire (Kreutzer, Leininger and Walland, 1987) as well as administering a series of standardised, objective neuropsychological tests including the oral administration of the Symbol Digit Modalities Test (Lezak, 1983). The investigators reported that findings were fairly inconsistent across the scales with the Pearson's correlation revealing that the cognitive, behavioural, communication and social impairments were only associated to the general functioning, communication, and roles subscales of the FAD. Regression analysis revealed that behavioural impairments were the strongest predictor of disruption to family general functioning, roles and communication patterns. On the other hand, five of the seven FAD scales (i.e., general functioning, communication, affective responsiveness, roles and

behaviour control) were associated with symbol digit performance. In each case greater levels of poorer performance on the test was associated with poorer family functioning. Similarly, Ponsford et al., (2004) found that cognitive, behavioural and emotional impairments based on the Structured Outcome Questionnaire (Ponsford, Olver, et al., 1999) were predictors of unhealthy family functioning. The mixed findings found by Kreutzer and his associates (1994b) led them to conclude that 'non traditional' methods may be necessary to fully understand the complex nature of the family.

Effects of Family Functioning on Psychological Distress

The research to date has established that neurobehavioural impairments have a significant influence on psychological distress experienced by spouses and parents of individual with TBI. Moreover, there is strong evidence that indicates neurobehavioural impairments disrupt marital and family relationships. The next avenue of investigation has focused on the interaction between disrupted family functioning and psychological distress amongst relatives of individuals with TBI. There has been limited research focusing on this important issue, but initial findings suggest that disruptive changes in family functioning increases the level of distress in caregivers (Lezak, 1978, 1986, 1988; Ponsford et al., 2003; Rosenbaum and Najansen, 1976). This approach remains under researched and will benefit from further investigation of the nature of the interaction between family and distress variables.

Effects of Neurobehavioural Impairments on Family Functioning and Psychological Distress Based on Stress Theory

In spite of the research on psychological distress and family functioning among relatives of people with TBI, little of this research has been conducted with reference to stress theory. As described previously, much of the empirical literature has focused on the contribution of the person with TBI to the development of psychological distress in caregivers, the relationship between neurobehavioural impairments and family functioning and the effects of changes in family functioning on psychological distress in relatives. Notwithstanding that each approach provides an important contribution to understanding stress in relatives of individuals with TBI, it is too restrictive to consider each of these approaches separately when endeavouring to understand the complex changes that take place in families after TBI.

A MODEL FOR UNDERSTANDING PSYCHOLOGICAL DISTRESS IN RELATIVES OF PEOPLE WITH SEVERE TBI

To address this challenge, Anderson, Parmenter and Mok devised a model of distress based on Hobfoll's Conservation of Resources theory (COR) of stress (1989; Hobfoll and Spielberger, 1992) and the McMaster Model of Family Functioning (Epstein et al., 1978), which facilitated the synthesis of the three former approaches on brain injury as a way of understanding the effect of neurobehavioural impairments on family functioning and

psychological distress among spouses who had partners with severe TBI (Anderson, 1999). The purpose of this section is to describe COR theory then show how this model can be used in a family systems context by incorporating the MMFF into the framework. Following this, the utility of the model will be described in the context of understanding psychological distress in relatives of people with TBI based on the initial research conducted by the authors.

COR theory has three primary dimensions of environment, resources and psychological stress, which are applicable to individual and family systems. The central dimension is resources, which people strive to obtain retain and protect because they are valued by them and any threat or loss will result in psychological distress. Subsequently, psychological distress is defined as 'a reaction to the environment in which there is (a) the threat of a net loss of resources (b) the net loss of resources or (c) a lack of resource gain following the investment of resources' (Hobfoll, 1989 p.516). There are four kinds of resources whose loss can lead to psychological distress. First, there are object resources, which are needed to meet basic survival needs. Examples include food, water, housing and transport. Second, there are condition resources, which provide access to other elements important for survival such as a good marriage, or a promotion at work. Third, there are personal resources such as self-esteem and self-efficacy, which are considered important for stress resistance. Then there are energy resources, which aid in the acquisition of other resources. Time and money are examples.

Environmental circumstances play an important part in threatening or depleting resources in COR theory. Elliott and Eisdorfer's (1982) normative perspective is advocated in which acute and chronic stressors such as serious medical illness, financial difficulties or a prolonged unhappy marriage can lead to behavioural disruption, deterioration in performance and psychological distress. On the other hand, people employ resources to offset loss and are generally motivated to build upon the resources they have to enrich their resource pool. Replacement is the most direct way to offset resources that have been lost. People can remarry following divorce or death of a spouse. If direct replacement is not feasible, indirect means may be appropriate. For instance, family members may seek the support of friends, relatives or professional organisations when caring for sick relatives. Nevertheless, according to Hobfoll (1989), employing resources for coping may be stressful in itself. If people expend energy and use up favours in order offset loss then it may be probable that the resources expended in coping may outstrip the benefits. Hence the outcome is likely to be less favourable.

People build upon their resources they have to enrich their resource pool. Investment in resources may be noticed in good marriages. In such marriages, both partners are constantly contributing from what they to each other and to the relationship. The contribution each partner makes is based on the underlying assumption that his/her investment will pay off in terms of love; esteem affection and security (Hobfoll, 1989). For example at the very beginning of a relationship couples learn to accommodate each other. They develop routines for eating, sleeping, and performing household tasks; managing finances, planning recreation and leisure activities that they will both enjoy. In this process a set of transactions is formed and then maintained by the couple, with each partner triggering and monitoring the behaviour of the other. On the other hand, if there is no net gain in the relationship after considerable resource investment, people will experience this as a net loss of resources. 'Their loss is imagined in relation to their expectations of the resources they would have had' (Hobfoll, 1989, p.35).

COR theory proposes that events can threaten and deplete family resources. At systems level family resources are referred to as dynamic into the family system, which describe how a family functions. The outcomes of the family system are reflected in the economic, domestic, health, socialization, affection, identity, and personal development of family members (Leaf, 1993). The McMaster Model of Family Functioning (MMFF) (Epstein, Bishop et al, 1978) that is made up of six dimensions of family life including problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control are family resources that are broadly congruent in character with COR theory. Subsequently, Anderson and associates to study distress in relatives of people with TBI in the context of COR theory adopted the MMFF.

Both models consider resources such as food, water, housing and transport as objects that are valued by people and an essential part of daily living. COR theory suggests conditions such as a stable marriage, promotion at work and power are important resources for survival and stability. Similarly, the MMFF describes role functioning where accountability, sexual fulfillment, nurturance and support, personal development and systems management are essential functions for assuring stability. Each dimension of the MMFF describes strategies that can be used to build upon and protect resources essential for effective family functioning. Problem solving, roles, communication and behaviour control are dimensions that are particularly valuable for this function. COR theory describes personal characteristics such as self-esteem and efficacy as being important for stress resistance. The MMFF on the other hand, does not address esteem and efficacy directly, but rather refers to the importance of affective involvement and affective responsiveness, which are resources that may contribute to high esteem and independence among family members.

Given the congruence between COR theory and the MMFF, the MMFF was adopted as the mediating variable in Hobfoll and Speilberger's (1992) definition of stress to assist further in the delineating variables relating to psychological distress in relatives of people who have sustained a severe TBI. Subsequently, psychological distress in the context of study family systems may be defined as a reaction to the stressors in the environment in which there is (a) the threat of a net loss of family resources, (b) the net loss of family resources, or (c) a lack of family resource gain following the investment of family resources as manifested by the level of family functioning. When the MMFF is considered in conjunction with Hobfoll's COR theory it can be argued that unhealthy or ineffective family functioning is indicative of a family situation where resources are under threat, actually lost or where there has been no significant gain after significant resource investment. On the other hand, healthy or effective family functioning represents those families that have successfully conserved resources, replaced resources that have been lost, or gained resources after significant investment.

TESTING THE MODEL

Spouses Study

Anderson and associates (2002) applied this model in the context of TBI so that they could study the effects of neurobehavioural impairments on family functioning and psychological distress in 64 spouse/caregivers with partners with severe TBI (see Figure1).

They proposed that chronic stressors or neurobehavioural impairments of the spouse with TBI would affect the psychological well being of the partner. This was based on the normative perspective that chronic stressors are likely to lead to deterioration in performance and psychological distress in the individual (Elliott and Eisdorfer, 1982; Hobfoll and Spielberger, 1992).

One of the authors interviewed the 64 spouse/caregivers who were recruited by health professionals from six brain injury rehabilitation programs in New South Wales. During the interviews, measures including the PCL (Kreutzer et al., 1987), the FAD (Epstein et al., 1983) and the Brief Symptom Inventory (BSI) (Derogatis, 1993) were administered. Drawing on this data, path analysis based on the AMOS 3.51 (Arbuckle, 1994) program was used to test the model. Initially a measurement model was specified that took into account all of the parameters in the model. However, the sample size was small relative to the number of parameters to be estimated. Therefore, path analysis was used to test seven composite variables including somatic cognitive, behavioural, communication and social impairments that served as predictors of the global scales representing family functioning and psychological distress.

Subsequently, they found behavioural, communication and social impairments experienced by the partner with TBI increased the symptoms of psychological distress in spouse/caregivers. Moreover, behavioural impairments were the strongest predictor from amongst these variables, which is generally congruent with other research. The model further assumed family functioning (family resources) mediated the relationship between chronic stressors and psychological distress in spouse/caregivers. This was based on COR theory which suggests that when people are confronted by chronic stressors then family resources are likely to be threatened or depleted as manifested by unhealthy family functioning, which leads to increased psychological distress. In line with the theory, spouse/caregivers who reported high levels of cognitive and behavioural impairments also identified significant disruption in family functioning. In addition, disrupted family functioning was associated with high levels of psychological distress. Moreover, indirect effects of behavioural and cognitive operating through family functioning intensified the level of psychological distress experienced by the spouse/caregivers.

This study was important for several reasons. It represented one of the first studies to use stress theory as a framework in the brain injury literature, and used a sophisticated path modelling technique to analyse the data. This model highlighted the relationship between chronic stressors (i.e. neurobehavioural impairments), family functioning and psychological distress. Moreover, the model also identified the significance of the mediating effect of family functioning (family resources) on psychological distress, which sheds more light on the complex nature of family functioning after TBI.

EFFECT OF NEUROBEHAVIOURAL IMPAIRMENTS ON FAMILY FUNCTIONING AND PSYCHOLOGICAL DISTRESS IN PARENTS AND SPOUSES WHEN A FAMILY MEMBER HAS A SEVERE TBI

The model of stress (Figure 1) has more recently been tested in a second phase of the research following this initial investigation, with the findings being reported for the first time

in this chapter. The purpose of this research was to use a mixed method approach to examine the structural effect of neurobehavioural impairments on family functioning and psychological distress in parents as intact couples as well as spouses when a family member has a severe TBI. This study broadened the focus on families to include parents as part of the cohort, which was combined with the sample of spouses/caregivers from the initial study (Anderson et al., 2002). This was done to provide a more holistic understanding of family relationships in the TBI population. Moreover, including parents in the study increased the sample size so that more variables representing family functioning and psychological distress could be explored in the path model. In addition, the findings from 10 in-depth interviews based on the McMaster Structured Interview of Family Functioning (McSIFF): "Couples" (Bishop, Keitner, et al., 1987) from the initial study are also reported for the first time. This provides a rich description of family functioning that complements the findings based on psychometric scales. Adopting a mixed method approach was done in line with the recommendation that non-traditional methods were needed to fully appreciate the complex nature of family functioning when a relative sustains a TBI (Kreutzer et al., 1994b).

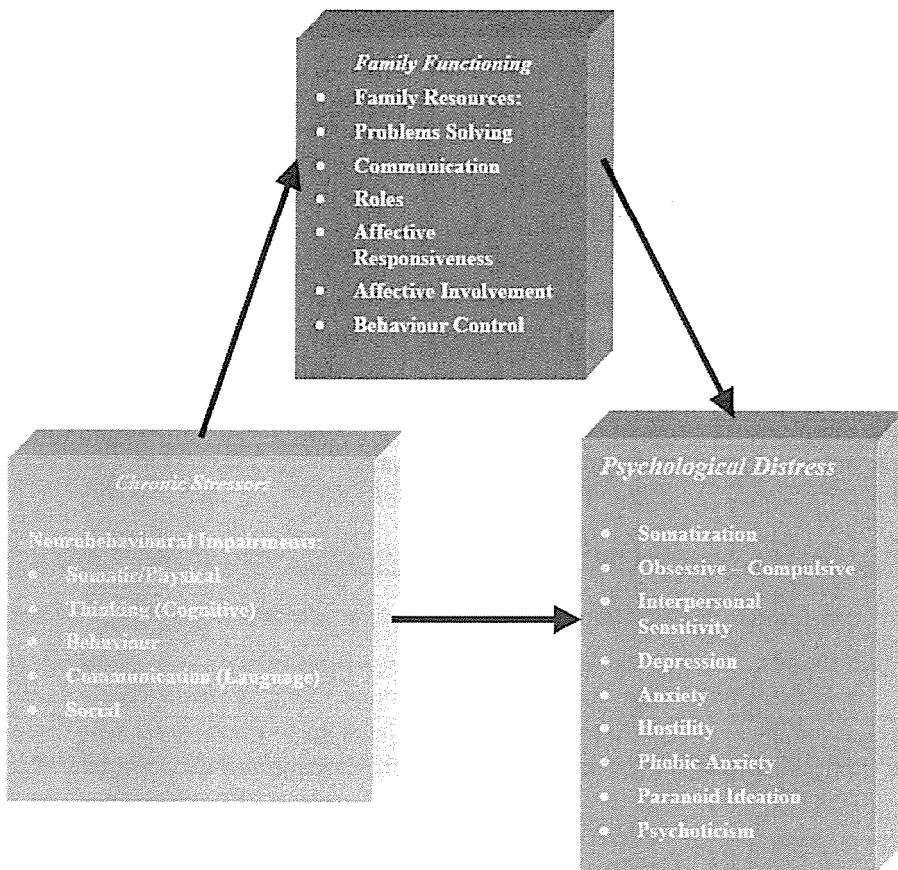


Figure 1. Model of psychological distress in relatives of people with TBI (From Anderson, M.I., Parmenter, T.R. Mok, M. (2002). The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: path model analysis. *Brain Injury*, 16, p.745. <http://www.tandf.co.uk>)

METHOD

The research was an *ex post facto* design utilising a cross sectional methodology to test the model linking neurobehavioural impairments of TBI, family functioning and psychological distress in relatives of individuals with severe TBI. Adopting this approach was appropriate since the model (Figure 1) effectively represented a recursive path diagram in which direct, indirect and mediating effects of variables are considered simultaneously in cross sectional designs (Biddle and Marlin, 1987).

Sample

Relatives

One hundred and four relatives (64 spouses and 40 parents) of partners or adult children (at least 18 years) with severe TBI were recruited from six brain injury rehabilitation programs in New South Wales, Australia. Relatives were included if they were living with the injured family member at the time of injury and after discharge from hospital, had primary responsibility for supporting the injured relative at home, had a family member with severe TBI with post-traumatic amnesia (PTA) greater than 24 hours or a period of coma of at least 6 hours if PTA was not known, and the injured relative had no known history of prior brain injury or psychiatric illness. Relatives had a mean age of 48 years and had been married or living with their partner for 23 years. The occupational status of the sample varied from professional and managerial positions to unskilled work, homemakers and retirees. This represented a broad range of families in terms of socio-economic status.

Characteristics of the Individual with TBI

The combined sample comprised 64 individuals with TBI from the first phase study, and an additional 20 people with TBI from the second phase. The 84 individuals (66 male and 18 female) were aged between 18 and 75 years, with a mean age of 36 years (missing data = 2). All these individuals had severe TBI based on length of PTA, or duration of coma if PTA was not known. Medical records showed 75 individuals had severe TBI with PTA scores ranging from two days to 224 days. The other nine individuals were in coma for more than 6 hours, suggesting that their injuries were severe as well. Time post injury ranged from 4 months to just over 15 years (mean = 3.3 years), which suggests these people were in the chronic phase of recovery. The majority of injuries (68%) resulted from road traffic accidents and the rest were caused by falls, assault or sporting activities.

Measures

Problem Checklist

The Problem Checklist (PCL) of the General Health and History Questionnaire (Kreutzer et al., 1987) was utilized to measure the range of domains of impairments that arise as sequelae of a TBI. The PCL is a self - administered pencil and paper test 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 5 subscales including: Somatic/physical (for example, “Headaches”), Thinking/cognition (for example, “Concentration is poor”), Behaviour (for example, “Threatens to hurt others”), Communication/language (for example, “Speech doesn’t make sense”) and Social (for example, “Rude to others”). The instrument has sound psychometric properties (Camplair, 1989; Anderson, 1999).

Family Assessment Device

The family functioning construct was operationalised using the FAD that is based on the respected McMaster Model of Family Functioning (Epstein, et al., 1978). The FAD is a self administered pencil and paper questionnaire consisting of 60 items on a 4-point Likert scale which is rated from Strongly Agree (1) to Strongly Disagree (4). The FAD consists of six scales that represent the hypothesis of the MMFF including: Problem solving (for example, “We solve every day problems around the house”), Communication (for example “People come right out and say things instead of hinting at them”), Roles (for example, “We make sure members meet their family responsibilities”), Affective Responsiveness (for example, “We are reluctant to show our affection for each other”), Affective Involvement (for example, “We are too self-centred”), and Behaviour Control (for example, “We have rules about hitting people”). Additionally, a General Functioning scale made up of 12 items assesses overall family effectiveness. It is designed to measure the structural and organisational properties of the family and the transactional patterns that occur in healthy and unhealthy families. The FAD is a reliable and valid instrument (Bishop and Miller, 1988; Kabacoff et al, 1990) that was developed for both clinical and research use. It is well accepted as a process of measuring family functioning in medical (Bishop, Evans et al., 1987; Bishop, Epstein et al., 1986) and psychiatric (Keitner, Miller et al., 1987; Miller, Kabacoff et al., 1986) and TBI populations (Kreutzer, Gervasio et al., 1994a; 1994b; Hall et al., 1994, Bragg et al., 1992; Anderson et al., 2002; Ponsford et al., 2003). The FAD is easily administered and can be completed within about 20 minutes by family members over the age of 12.

Structured Interview

The McSIFF “Couples” was used with 10 volunteers who perceived that family functioning was “healthy” (n = 3) or “unhealthy” (n =7) according to the FAD scales. Conducting a follow up interview of this nature enabled the investigator to explore in greater depth each dimension of the McMaster model. The FAD gives a single rating for each dimension, whereas, the McSIFF assisted in determining more specific difficulties family members were experiencing in sub components of each dimension (Bishop and Miller, 1988).

The McSIFF is designed for couples, where each partner is given the opportunity to discuss his or her point of view on family functioning. However, the spouse/caregiver was the primary focus in this study and subsequently the interview schedule was modified slightly by rephrasing some questions to obtain information on family functioning from the spouse/caregiver’s perspective. Adopting this approach may have certain limitations from a family systems view. Nonetheless, the spouse/caregiver is a central family sub-system, and his/her ability to adapt to changes in the family due to the presence of a partner with a head injury may be critical to the survival of the family unit. As such, the spouse/caregiver in this study was subject to family systems analysis, just as other family sub-systems are assessed. Whitchurch and Constantine (1993) argue, ‘The GST (general systems theory) assumption of

wholeness and characteristic of interdependence do not preclude looking at individual members of families, as long as individuals are regarded as sub systems *of* and not isolates *from* the family' (p. 349).

Brief Symptom Inventory

The psychological distress construct was operationalised by means of the BSI, which is an abridged version of the SCL-90-R (Derogatis, 1975). The BSI is a self-administered pencil and paper questionnaire consisting of 53 statements 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 non-clinical individuals from nine primary symptom dimensions and three global indices: Somatization, 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 and non-clinical (Derogatis, 1993) and TBI populations (Kreutzer et al., 1994a, 1994b; Gervasio and Kreutzer, 1997; Anderson et al., 2002). The reliability and validity of the BSI is very good and has been extensively reported (Derogatis, 1993). We assessed the somatization, obsessive-compulsive, depression, anxiety, hostility, and psychoticism and global severity index scores in the path model because these symptoms are considered most relevant in the context of the distress experienced by relatives who have a family member with TBI (Kreutzer et al., 1994b).

Analysis of Data

The major form of analysis was path analysis, which was used to address the structural effects of neurobehavioral impairments on family functioning and psychological distress. The traditional approach to testing structural equation models (SEM) was adopted, which involved testing the measurement and structural components of the model (figure 2) simultaneously in the AMOS 4 (Arbuckle and Wothke, 1999) computer program. In SEM the measurement component is established using confirmatory factor analysis (CFA) and the structural or path model is determined using path analysis. CFA is an important preliminary step in the analysis of full latent variable models because it determines the validity of the measurement model. Once it is known that the measurement model is operating adequately, the findings related to the structural model can be viewed with more confidence (Bryne, 2001). The measurement component can be demonstrated by the manner the latent variable neurobehavioural impairments is being measured by 5 observed variables including somatic, cognitive, behaviour communication, and social impairments. Since there were three latent variables in the model, namely neurobehavioural impairments, family functioning and psychological distress, these three measurement models had to be established for all the latent variables. In the second component, i.e. the structural component, the structural effects of neurobehavioural impairments on family functioning that, in turn, influences psychological distress were examined. Furthermore, the structural effects of neurobehavioral impairments on psychological distress were assessed as well.

The audio taped interviews from the McSIFF were transcribed and each dimension was rated as healthy or unhealthy based on the answers given by the spouse/caregivers to the questions and probes provided in the interview schedule. Then the investigator carefully collated the data to search for common themes in the structure, organisation and transactional

patterns of the family from the spouse/caregivers point of view, which were checked and confirmed by the co researchers.

RESULTS

The results will be presented in three sections. First, descriptive data reporting on the severity of neurobehavioural impairments experienced by the person with TBI as rated by family members, the levels of disruption to family functioning and the symptoms of psychological distress experienced by relatives will be presented. Second, the results of the structural equation model testing the relationships between neurobehavioural problems, family functioning and psychological distress will be described. Finally, the findings from the qualitative interviews will be presented.

The nature of the neurobehavioural impairments reported by relatives' (Table 1) found that cognition/thinking impairments were most frequently reported, with an average PCL score of 2.10 (SD = 0.59), just above the mid-point on the scale. On the other hand, behaviour, somatic, social and communication scores were just below the mid-point, with social impairments (mean = 1.8; SD = 0.58) being the lowest score.

Table 1. Mean neurobehavioural impairment scores, and standard deviations reported by relatives

Problem check list scale	Relatives (n = 104)		Parent (n =40)		Spouse (n = 64)	
	Mean Score	(SD)	Mean Score	(SD)	Mean Score	SD
Somatic	1.91	0.53	1.68	0.45	2.06	0.53
Thinking	2.10	0.59	1.85	0.60	2.19	0.55
Behaviour	1.93	0.54	1.78	0.51	2.04	0.53
Communication	1.79	0.57	1.70	0.49	1.85	0.62
Social	1.87	0.58	1.65	0.50	2.00	0.58

Table 2. Mean scores for family functioning and proportion of unhealthy family functioning in relatives based on the FAD (N = 104)

FAD Scale	Mean Score	(SD)	% Above Cut Offs	FAD Cut Offs
Problem Solving	2.06	0.43	29%	2.2.
Communication	2.21	0.47	60%	2.2
Roles	2.28	0.41	53%	2.3
Affective Responsiveness	2.26	0.56	52%	2.2
Affective Involvement	2.09	0.45	59%	2.1
Behaviour Control	1.88	0.44	50%	1.9
General Functioning	2.03	0.51	58%	2.0

FAD = Family Assessment Device

Levels of family functioning reported by relatives are presented in Table 2. The mean scores exceeded the “cutoff” scores on three of the seven subscales including the general functioning scale, which indicates relatives were experiencing a diverse range of structural, organisational and transactional difficulties. Moreover, the mean scores for each scale are higher than the scores reported in normal and other TBI populations (Kabacoff et al., 1990; Ponsford et al., 2003). The highest level of unhealthy functioning was reported on the communication (60%) subscale, suggesting that family members were having difficulties discussing their feelings to each other and other family issues. By contrast, fewer (27%) reported ineffective problem solving skills, which is consistent with previous findings (Kreutzer et al., 1994a).

The symptoms of psychological distress experienced by relatives are reported in Table 3. Raw scores were converted to T scores based on non-patient norms. The group means for relatives exceeded the means for non-patient norms (T score = 50) for every subscale including the BSI, which indicates that the relatives were experiencing a broad range of distress symptoms. This finding was remarkably similar to the findings by Kreutzer et al., (1994a) and Gervasio et al. (1997). Moreover, 63 (61%) relatives were experiencing psychological distress at caseness level. Specifically, the greatest levels of distress were generalised distress based on the GSI (43%), obsessive-compulsive (42%), psychoticism (41%) and depression (40%). Whereas, lower frequencies were reported for somatization (31%) anxiety (34%) and hostility (34%), which is slightly higher than the distress reported in previous research (Kreutzer et al., 1994a).

Table 3. Mean T scores, standard deviations and percent of relatives demonstrating caseness on the BSI (N =104)

BSI Scale	Mean T Score	(SD)	Caseness (%)
<i>Somatization</i>	54.5	11.20	31
Obsessive-Compulsive	59.0	11.35	42
Depression	58.61	10.50	40
Anxiety	56.01	11.48	34
Hostility	57.03	11.30	34
Psychoticism	58.54	11.30	41
Global Severity Index	58.66	11.98	43

The Effects of Neurobehavioural Impairments on Family Functioning and Psychological Distress in Spouse/Caregivers and Parents of Adult Children with Severe TBI

First, the data was screened using descriptive and correlational techniques to determine the most suitable variables to be included in the model for testing. Correlation coefficients between variables that were less than 0.3 were not included in the model. Subsequently, five variables were excluded from the model including variables communication, affective responsiveness, affective involvement and behaviour control from the FAD scales and somatisation from the BSI. Although the correlation coefficient between social impairments and role functioning ($r = 0.26$) was weak the variables were retained in the model for two important reasons. Statistical significance may be related to sample size; ‘nonsignificant

parameters can be indicative of a sample size that is too small' (Byrne, 2001, p. 76). If the sample had been larger statistical significance may have been demonstrated amongst these variables. Second, non-significant parameters may be retained for substantive theoretical interests (Schumacker and Lomax, 1996). In one investigation Kreutzer et al (1994) showed social impairments was associated with impaired role functioning, albeit that behavioural impairments was the strongest predictor amongst these variables. Therefore, it makes sense to keep this variable in the model so that comparisons can be made with other populations when a family member has TBI.

Correlations among the 13 variables of the matrix ranged from 0.26 to 0.84 with 41 % of the correlations being above 0.50. The structural equation model was fitted to the correlation matrix using the computer program AMOS 4.0 (Arbuckle and Wothke, 1999). The technique used was the model generating approach described by Jöreskog and Sörbom (1993) in which the researcher specifies a tentative theory-driven model, which on the basis of the model's fit to the data, is successively modified and retested until on a combination of statistical and substantive criteria an optimal fit is obtained.

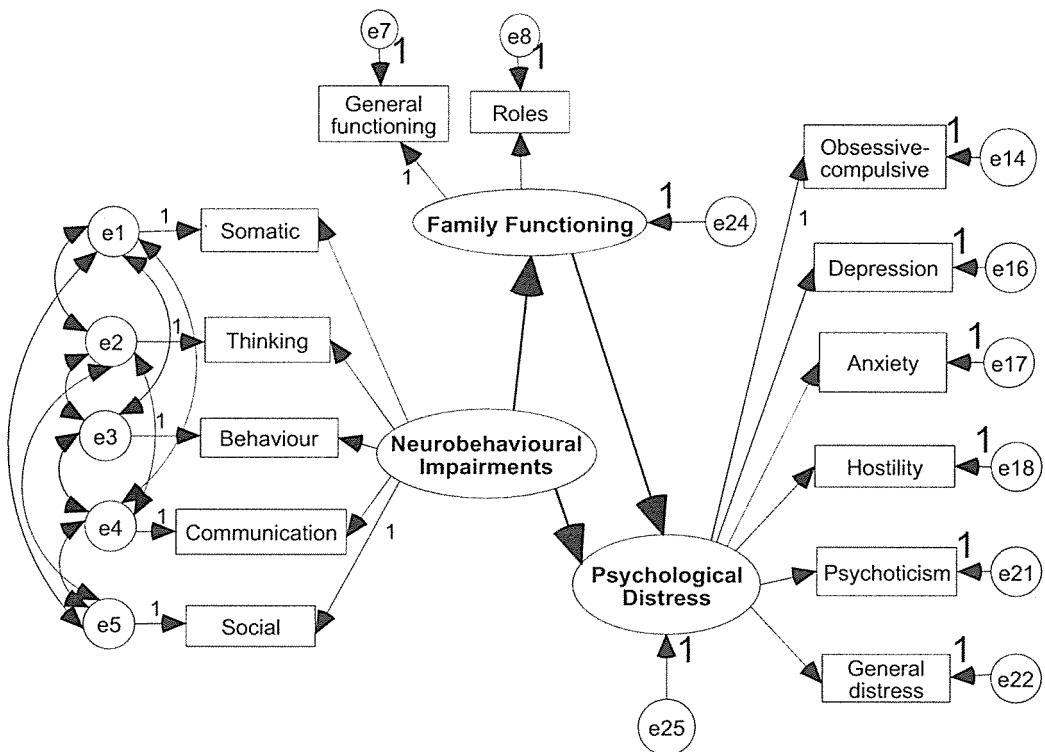


Figure 2. Final path model of psychological distress in relatives

The tentative model was tested and an optimal fit was achieved in the initial phase of analysis (Figure 2). The neurobehavioural impairments construct was operationalised by five observed variables corresponding to five dimensions consisting of somatic, thinking (cognition), behaviour, communication, and social impairments. Neurobehavioural impairments so defined was found empirically to have had an impact on family functioning and psychological distress. Table 6 presents the results for the fitted final model (Figure 2).

The structural coefficients (standardised β 's) between the variables are the path coefficients for the model. The unstandardised coefficients and their standard error and t ratio are reported for totality. Goodness of fit indices for the model indicates a very acceptable agreement between the data and the model ($\chi^2 = 51.885$, $p = 0.518$; GFI = 0.929; CFI = 1.000; NFI = 0.952 and RMSEA = 0.000). Models with values of RMSEA less than 0.05 indicate a close fit between the data and the model (MacCullum and Hong, 1997), which indicates the current model fits the data exceptionally well and thus providing strong empirical evidence to support the theoretical model on psychological distress.

Table 6. Neurobehavioural impairments, family functioning and psychological distress: fitted AMOS final Model (N=104)

Regression Weights	Estimate in Raw Units	Standard Error	t Ratio	Standard Estimate (β)
Family functioning-Neurobehavioural impairments	0.565	0.132	4.292	0.578
Psychological distress – Neurobehavioural impairments	13.648	3.040	4.490	0.630
Psychological Distress- Family Functioning	5.485	2.672	2.053	0.247
Goodness-of-Fit Measures:				
Chi-square (χ^2)	51.885			
Degrees of Freedom (df)	53			
Ratio of Chi-square to degrees of freedom is less than 1				
Goodness-of-Fit Index (GFI)	0.929			
Normative Fit Index (NFI)	0.952			
Comparative Fit Index (CFI)	1.000			
RMSEA	0.000			

Total, Direct and Indirect Effects

The observed variables somatic, cognitive, behaviour, communication and social impairments did not have a significant direct or indirect effect on any of the endogenous variables in the model. Nevertheless, neurobehavioural impairments as a construct had a significant direct effect on family functioning ($\beta = 0.578$). This means relatives who are caring for spouses or children with many neurobehavioural impairments were likely to report unhealthy or ineffective family functioning. Furthermore, neurobehavioural impairments had a significant direct effect on psychological distress ($\beta = 0.630$), which suggests relatives were very distressed by the neurobehavioural impairments experienced by the spouse or adult child with TBI. The model indicates to a lesser extent that family functioning has a significant direct effect ($\beta = 0.247$) on psychological distress, which suggests unhealthy family functioning may increase the level of psychological distress experienced by spouses and parents of people with TBI.

Total effects and indirect effects were examined to determine the influence of neurobehavioural impairments on psychological distress via the mediating variable family functioning. Neurobehavioural impairments had a significant total effect ($\beta = 0.773$) and an indirect effect ($\beta = 0.143$) on psychological distress via family functioning. This indicates symptoms of psychological distress experienced by parents and spouses were intensified by neurobehavioural impairments through family functioning.

Neurobehavioural impairments had a significant total effect ($\beta = 0.467$) on the observed variable general functioning. This means the neurobehavioural impairments experienced by relatives with TBI had adversely affected the organisational, structural and transactional patterns in the family. Neurobehavioural impairments also had a significant total effect ($\beta = 0.447$) on the observed variable roles, suggesting that role functioning was ineffective because of the neurobehavioural impairments manifested by spouses and adult children with TBI.

Neurobehavioural impairments had a significant total effect on the observed variables psychoticism ($\beta = 0.664$), hostility ($\beta = 0.589$), anxiety ($\beta = 0.598$), depression ($\beta = 0.728$), obsessive - compulsive ($\beta = 0.624$) and general distress ($\beta = 0.738$). This suggests parents and spouses who reported frequent neurobehavioural impairments are likely to report a broad range of symptoms of distress.

The effects of family functioning on the observed variables representing psychological distress were of an indirect nature. Family functioning had an indirect effect on psychoticism ($\beta = 0.213$) hostility ($\beta = 0.188$), anxiety ($\beta = 0.191$), depression ($\beta = 0.233$), obsessive-compulsive ($\beta = 0.20$) and general distress ($\beta = 0.236$) via psychological distress. This indicates parents and spouses of relatives with TBI experience a broad range of symptoms of distress, which were intensified by ineffective family functioning.

In-Depth Interviews

The in-depth interviews conducted to further illustrate the changes in family functioning as a consequence of living with a spouse with traumatic brain injury.

Problem Solving

The majority ($n=9$) of spouse/caregivers were primary problem solvers in the family; given the cognitive and behavioural impairments experienced by their partners with TBI. Problem solving involved spouse/caregivers resolving instrumental and affective issues that threatened the integrity and functional capacity of the family. In one case, a female spouse/caregiver had difficulties adjusting to assuming authority, especially since she was used to viewing her husband as a leader in the home prior to his injury. She explained her situation like this: 'He was always the leader...I was quite happy with that because I knew he could do the job, and trusted him completely. ... I don't like it (her new role), but I do my best.' In another case the wife had a great deal of difficulty solving problems because her partner, 14 years post injury, was reluctant to be discuss instrumental or affective issues. She described the problem solving process like this: 'He is very uncompromisable- which you may find with people with head injury. They can't see around corners. They can't see the full picture.' Subsequently, she would give in to his demands most of the time to the point where 'it wrecks your life.'

The remaining spouse/caregivers interviewed believed it was important to involve their partners with TBI in the problem solving process to protect the partner's esteem and reduce conflict within the marital dyad. The challenge of this approach was the time it took to resolve problems particularly amongst partners with TBI who appeared to have impaired

executive functions. The partners with TBI lacked the ability to make quick decisions or comprehend complex problems, and follow through with plans. Moreover, partners with TBI had difficulty profiting from the consequences of their behaviour, as manifested by repeated mistakes in judgement. For instance, one couple had ongoing problems with budgeting, given the female partner had difficulties keeping to the shopping list. Nonetheless, the husband worked with his wife to by assisting with the preparation of the shopping list in the anticipation that she would learn from her mistakes. For instance, after helping his wife with the shopping list, 'she'll still buy the same packet of cornflakes every week whether we need it or not.' Her memory problems made him feel frustrated and angry at times to the point of driving him 'crazy'. This type of scenario was the experience of other spouse/caregivers. Nevertheless, they found the collaborative approach to problem solving and decision-making beneficial over the long term even though the process was demanding and time consuming.

Communication

The majority of spouse/caregivers reported ineffective communication patterns between couples. Six spouse/caregivers were not satisfied with the quantity or amount of time spent making conversation with their partners. According to four spouse/caregivers their partners preferred not to make conversation; and one female spouse/caregiver complained that she did not have sufficient time in the daily schedule to spend talking with her partner or family. Typical comments, which illustrate these themes, include: 'We could drive from here to Sydney and, unless I spoke, Barry would be quite happy not to speak'. Or ... 'it's like pulling teeth to get information.' In contrast, one male spouse/caregiver complained that his wife talked endlessly, which distracted from his daily routine to the point where he would tell her to 'shut up'.

The quality of communication between most of the couples was disrupted by behavioural, cognitive and or physical impairments experienced by the partners with TBI. Three partners with TBI had hearing as well as memory impairments, which made communication with their partners frustrating. Typical comments were: 'She's forgotten what was said in the morning and we do it all again in the afternoon.' Moreover, the majority of spouse/caregivers had difficulties talking straightforwardly about mood. In most situations the spouse/caregiver was hesitant to talk clearly and directly about feelings of sadness or anger, because communication of this nature usually triggered anger or loss of temper by the partner with TBI. In one case, the wife described it like this: ... 'you don't tell all the worries ... it's like if you are writing a letter overseas, you only tell them the nice bits.' A husband described the communicating with his wife as 'circumspect.' 'She has a bad temper which can get out of control... therefore there's no point in me just making it worse.' 'So you work in and you can sort of get away with it'.

Roles

Roles are the means by which family tasks including provision of resources, personal development, nurturance and support, adult sexual satisfaction and systems maintenance and management are allocated and carried out. Since the time of injury all of the

spouse/caregivers (n=10) interviewed assumed primary responsibility for providing most resources for their families. These husbands and wives were ultimately responsible for providing money (or managing a pension), food, clothing and housing: although it was reported that the majority (n = 8) of the partners with injuries did play a minor role in assisting with some tasks such as shopping, cleaning and yard work. In one case, the husband had recovered sufficiently to return to work on a part time basis with his wage supplemented by workers compensation. One husband explained: 'there are the memory problems and like even house work as she goes around the house, ... she forgets things and leaves the stove on, ... and sometimes it is caring for the baby too.' In another case the wife explained: 'Every single day Paul has to fight to keep his concentration to remember things and keep going.' In another case, role allocation was almost impossible for a wife with a husband who refused to be accountable for jobs around the house. This was reflected in his comment: 'I've got a brain injury, I can't do things like that, I can't remember.'

Consequently, the majority (n = 9) of the participants interviewed felt overburdened and by the jobs they were performing. This was expressed in similar ways by the carers:

'For three years my life's been from early in the morning, going to work, coming back home, doing the cooking.... By the time I finish in the kitchen and I do the cleaning up I never go to bed before 12.'

'I swore I'd never, ever get to learn to cut the bloody grass but I did. ... And it's a big garden and it's a big house and there's a lot of maintenance. ... But now I feel as if everything's getting too much.'

Other carers commented:

'it's a crazy, crazy situation at times' or 'I just think, I am going mad.'

Possibly, one of the most telling aspects of resource provision was the difficulty some spouse/caregivers had managing family finances. And there are several reasons as to why this might be so. Seven husbands with TBI were receiving the pension or workers compensation, which was substantially less than the amount of income the families had been accustomed. Furthermore, some husbands no longer possessed the skills to perform proper maintenance in and around the home, which subsequently required the use of a tradesperson. For three wives, the combination of reduced income and their partner's reduced ability to carry out routine maintenance added to the cost of living, resulting in delays in making large purchases, and carrying out routine maintenance and repairs to the home and motor cars. In one other case, a husband's gambling substantially reduced his wife's capacity to balance the family budget as described in her comment: Well, we do have financial problems because we're on workers compensation which is ...\$316/\$317 a week and he has \$100 out of that for gambling...'. And this spouse explained the financial consequences with the following statement: 'Shopping for clothes, I haven't done any of that for two years because I haven't had any money for two years.' Further illustrating the nature of the burden the spouse/caregivers were experiencing.

A further theme in the role dimension was the lack of nurturance and support between couples, as reported by the spouse/caregiver. This often left the spouses feeling isolated and lonely. Consequently, some wives reported relying on alcohol and cigarette smoking as a

coping strategy. For instance when the participants were asked: When things get to you or you have had a bad day, whom do you go to? Most of the spouse/caregivers responded: 'Nobody' or 'Myself.' In one case, the wife stated: 'The bottle. Nobody else.' Another wife simply stated: 'Have another fag, have another fag.' Turning to their partners was difficult because of the anger, frustration or indifference their partners exhibited when communication of this nature was attempted. In one case, the injured husband would respond: 'I'm the one with brain damage you know; try to understand how hard it is for me.' In another case, a wife stated: 'He reacts so badly so I don't turn to him anymore.' Consequently, most of the spouse kept their thoughts and feelings to themselves.

Just over half the spouse/caregivers had problems with sexual functioning. Five wives were not satisfied with the amount of affection in the relationship based on their partners' difficulty in expressing empathy and interpersonal sensitivity. Typically the wives missed the physical affection and intimate talk that their husbands used to share with them. This was best illustrated in a wife's comment: 'I thought to myself last night as I was nodding off to sleep... Love to men is a thing apart 'tis women's whole existence.' The majority of wives ($n = 5$) were not satisfied with the frequency of sex. Three of the husbands with TBI were impotent, and one male spouse had severe orthopaedic problems that made engaging in sex painful and difficult. One wife was not concerned about the frequency of sex because sex never played a major part in their relationship before the injury. The majority of male spouse/caregivers were not satisfied with the level of affection in the relationship. Although in one case, there was no difficulty in sharing intimate moments together. The husbands reported that they were generally satisfied with the frequency of sex; although in two cases, physical limitations required careful planning to assure sexual intercourse was mutually satisfying.

Lack of personal development was another theme in the role dimension of the study. More than half ($n = 6$) of the spouse/caregivers were not satisfied with the level of personal development achieved in their lives. One wife resented taking on a dual role as homemaker and full time income earner. By contrast, a husband regretted giving up his career as a manager of a large motor dealership to become a full time carer. In another case, a 60-year-old school principal delayed her retirement until the future was more certain. In addition, social activities were put on indefinite hold or severely curtailed. For example, family vacations were delayed or shortened; and social interaction with friends and acquaintances were sharply limited because the social and behavioural impairments of the partner with TBI and financial restrictions. This outcome was depicted in the following comment:

... 'when we've gone away (on vacation) he's found it a bit hard to handle because it throws him very quickly and easily. The unknown or the new, if something's new it doesn't end up being a break; it ends up being a stress because I have to handle him so carefully.'

On the other hand, three participants were satisfied with personal development. In particular, the male spouse/caregivers had the opportunity to pursue their personal interests. For instance, one husband went roller-skating and surfing as a way of reducing his stress. He also added interests such as bush walking and camping so that his wife could participate. In another case, a husband planned his day so that he could spend time in his garden. Moreover, two of the male caregivers had access to respite. In one case the wife with TBI would go on holidays with her father twice every year. In another case, the mother-in-law would take her

injured daughter shopping each week as a way of giving her son some time to himself. None of the female spouse/caregivers interviewed indicated that they had access to respite.

When managing the family system, the majority of spouse/caregivers ($n = 9$) had the authority to make a final decision on most issues. Although, in one case an 'aggressive uncompromising' husband had the final word '99.9 percent of the time.' A collaborative approach to decision making was often adopted by the spouse/caregivers as a way protecting the partner's esteem and avoid arguments. In five cases, where the partners concentration was poor and their capacity to make a decision was impaired, spouses carefully negotiated a positive outcome by introducing an issue that needed a decision, allowed the partner time to consider the matter, then entered into further discussion to reach a consensus (the decision desired by the spouse/caregiver). Spouses found the collaborative approach time consuming and frustrating but the outcome was usually fruitful. In one case, (a scenario echoed by others) a wife explained: '...if he thinks that I'm taking away his decision making powers ... his esteem takes a nose dive...what I've got to do is to present him with the arguments...give him time to think it through ... and usually he will come around.'

An important theme in this study was loss of contact and support from friends and relatives after the partner experienced TBI. There was a sense of isolation and loneliness among four of the spouse/caregivers because their parents were either deceased, living interstate or overseas, and or were too old or frail to provide any useful practical or emotional support. In one case, the wife had the support of friends immediately after her husband was injured but ... 'they've got on with their lives and there's the contact but not the support. 'They've just distanced themselves ... and , yes, I do, I feel very, very much alone, very alone these days.'

Furthermore, people did not seem to understand the long-term consequences of TBI and had unrealistic expectations of the family based the perception that the injured person had made a sufficient recovery. In one case, a wife found it very stressful organising her husband and five children to visit her mother and father-in-laws home. When she tried to explain her husband's condition they would reply: 'He's back at work, he's had his pay out, he looks all right, he sounds okay. Therefore, he is okay.' This was a sentiment reflected by other spouses as well.

Affective Responsiveness

Affective responsiveness is the expression of emotions among family members. The majority of spouse/caregivers reported that the marital dyad did not have the capacity to express the full range of welfare and emergency emotions effectively. Welfare emotions encompass feelings of love, tenderness, joy, concern and warmth toward fellow members; and emergency emotions are those aspects that involve anger, fear, sadness and depression. On the one hand, spouse/caregivers freely expressed tenderness and concern toward their partners and other family members. In one case a wife explained: ... 'for all the things he does and says, Barry isn't a bad person, and he is my husband and we are a family, and therefore, he's somebody I should care for and take care of ...'. By contrast, according to the spouse/caregivers, more than half ($n = 6$) of the partners with TBI had difficulties reciprocating these kinds of feelings. Furthermore, the majority ($n = 7$) of the partners with TBI often expressed negative emotions that were inappropriate to the situation. In one case

the wife explained: 'He can lose his temper over anything, ...he will just thump the chair or thump his hand just be verbally-have a go at me.' In another case, the husband explained: 'It (losing temper) could be anything from any sort of criticism if it's to direct.' Consequently, most of the spouse/caregivers ($n = 9$) remained cautious about expressing feelings of anger, sadness or depression with their partners out of concern for negative repercussions.

Typically, spouse/caregivers had internalised feelings of anger or depression about the losses they had experienced. In one case, a 61-year-old wife explained it like this: 'I've lost my best friend. I feel at times I'm living with a totally different person. ...I'm sad about the things I've lost.... If I tried to tell him it would only make him feel worse.' Similarly, a 59 year old husband, three years after his wife's injury commented: 'I've lost part of Jan, ...I feel sad about the whole situation.' Nevertheless, in this case the couple had learned to communicate directly and clearly about the personal losses they had experienced.

Affective Involvement

Affective involvement is the extent to which family members show concern and caring for one another. Affective involvement may range from absence of involvement to symbiotic (very intense involvement) with empathetic involvement about mid point in the range. Absence of involvement and symbiotic involvement are considered extreme and ineffective, whereas empathetic involvement is regarded as ideal. Only three spouse/caregivers reported empathetic involvement within the dyad. These couples showed empathy for each other and individual interests were valued. Typically, these couples encouraged each other to pursue various activities that were appealing and acknowledged that they cared for each other. In one case, a retired couple did volunteer work at the local primary school. The wife was a former maths teacher and her husband taught carpentry, although 'he was slower with his hands' since his injury three years earlier. His wife accepted his condition and showed a genuine interest in him by asking him how he was progressing with his students, admiring his finished woodwork, and assisting him with picking up supplies. She further explained: 'And sometimes I think if he talks over with me what he is going to do with the boys it's a help to him.' Similarly, her husband also showed an interest in her activities. He demonstrated this by spending time with her shopping, watching her play tennis, discussing her day at crafts, and planning their next holiday. This approach was reflected by the other spouse/caregivers as well. Empathetic involvement was central in the relationship because as one spouse put it: 'If we didn't (care for each other) we probably would have ended up living in different places a long time ago.'

The remaining spouse/caregivers frequently demonstrated empathetic involvement toward their partners and other family members, despite reporting that their partners with TBI demonstrated narcissistic involvement or a self-centred attitude much of the time. In two families the male partners showed very little concern or interest in their wives activities. In one case, the wife made adjustments to her busy schedule by letting her husband use the family car to attend brain injury association meetings and disabled fishing club outings. By contrast, her interests and activities, which were few and far between, were rarely encouraged or acknowledged by him. Nonetheless, her commitment to him was strong because she believed his shortcomings were a consequence of his TBI and he was slowly improving. This sentiment was echoed by other spouse/caregivers as well.

Behaviour Control

Behaviour control, which refers to rules and standards, was a problem in several families. Three female spouse/caregivers reported alcohol problems, which they claimed was associated with the stress of living with their “changed” partners. In one case the wife was in the process of admitting herself into hospital for treatment, because of her abnormal liver function tests and a drink driving charge. In another case, the wife would drink late into the night while waiting for her husband to clear the bed of his ‘numbers’ for state lotteries. One couple had weight problems because the wife with TBI insisted on preparing three cooked meals a day, and any attempt to reason with her was met with angry protests. Moreover, in this case, the wife’s memory was so impaired that she could consume up to three breakfasts in a morning if she was not monitored closely.

The majority of female spouse/caregivers were embarrassed in public by the actions of their partners, although in two cases spouses felt more embarrassed for the partners rather than themselves. Typically, spouse/caregivers were apprehensive about antisocial behaviour such as poor table manners in at restaurants; arguments with people in shopping malls, and loss of temper with friends at social gatherings. In one case the wife stated: ... ‘the thing that I dread the most is that he’ll lose his temper in public.... It’s like a rage, an uncontrollable rage.’ Similarly, in another case, a wife explained: ‘When he gets angry it’s embarrassing and frightening. He shouts at me right in front of everybody.’ By contrast, two male spouse/caregivers were not embarrassed because their wives were “placid” and “even tempered.” Furthermore, 5 spouse/caregivers reported a decrease in the incidence of anti social behaviour as time since injury elapsed.

SUMMARY

This analysis has shown neurobehavioral impairments experienced by the relative with TBI to have a moderate adverse influence directly and indirectly on psychological distress. Relatives reporting high levels of neurobehavioral impairments also reported high levels of psychological distress. Relatives reporting high levels of neurobehavioural impairments also identified significant disruption in family functioning. Furthermore, disrupted family functioning was associated with high levels of psychological distress. Significantly, relative distress was intensified by the indirect effects of neurobehavioural impairments mediated by the disruption to family functioning. The interview data supported the model, but also found that neurobehavioural impairments disrupted problem solving, affective responsiveness, affective involvement, communication and behaviour control among family members, an issue not detected by the standardised scales.

DISCUSSION

This ex post facto study adopted a contemporary theory of stress as a framework, which synthesizes TBI, family systems and distress variables in a way that provides a more comprehensive understanding of family responses. Guided by the theoretical framework the

study intended to examine predominately neurobehavioural influences affecting family functioning and psychological distress among relatives of individuals with severe TBI. The main thesis was the relatives' perceptions of the nature of the neurobehavioural impairments experienced by the injured family member would powerfully influence the level of family functioning and the extent of psychological distress reported by the relatives. In Hobfoll and Speilberger's (1992) terms, the relatives' environment was dominated by chronic stressors, which have the potential to threaten or deplete family resources, which would largely determine the level of distress experienced.

Interaction Effect between Psychological Distress, Family Functioning and Psychological Distress

Consistent with COR theory (Hobfoll and Spielberger, 1992) and the MMFF (Epstien et al., 1978) chronic stressors, or neurobehavioral impairments of TBI increased the level of distress experienced by relatives via the mediating variable, family functioning. In other words, neurobehavioural impairments threatened or depleted family resources as manifested by ineffective family functioning, leaving the relative feeling distressed, which is consistent with the findings in the first phase of the study on spouse/caregivers (Anderson, 2002). Furthermore, neurobehavioural impairments had a direct effect on psychological distress in relatives, which is consistent with the empirical literature (Gillen et al 1998, Kinsella, 1991; Kreutzer et al, 1994b; Ponsford et al., 2003) and theoretical literature (Elliott and Eisdorfer, 1982). However, none of the observed variables representing the neurobehavioural impairment construct predicted family functioning or psychological distress in the model, which was different to the findings in the initial study where behavioural and cognitive impairments were predictors of family functioning and psychological distress. A possible explanation may be related to parents reporting fewer neurobehavioural impairments than spouses (Table 1). Subsequently further testing with two separate path models for parents and spouses will be required, which was not possible in this study because the sample size of the parents was small ($n = 40$) relative to the number of parameters in the model.

Effects of Neurobehavioural Impairments on Family Functioning

Consistent with COR theory, previous research (Froch and Gruber, 1997; Kreutzer et al, 1994b) and clinical observations (Lezak, 1978) the model showed neurobehavioural impairments disrupted role functioning (path coefficient of neurobehavioural impairments and role functioning = 0.447) and general functioning (path coefficient of neurobehavioural impairments and family functioning = 0.467) based on the FAD, which suggests that these families were having problems with the general structure, organisation and transactional patterns in the family. Moreover, the findings were enhanced by the in-depth interviews, which indicated the range of specific mechanisms through which cognitive and behavioural impairments disrupted each dimension of family functioning, including the spouse/caregivers lack of power to make decisions, financial difficulties, high burden, poor sex life, little or no support from friends and relatives, loneliness, lack of involvement in the marital dyad, lack of personal development, and substance misuse. This outcome adds support to the importance of

using non-traditional approaches to understanding the complex nature of family dynamics following TBI.

Effects of Family Functioning on Psychological Distress

In agreement with the model and previous research (Anderson et al 2002; Lezak, 1978; Marsh et al., 1998; Ponsford et al., 2003; Rosenbaum and Najansen, 1976) family functioning had a direct effect (path coefficient between family functioning and psychological distress = 0.247) on psychological distress in relatives, which suggests disrupted family functioning may increase the level of symptoms of distress in caregivers. Moreover, ineffective family functioning was indirectly associated with every BSI subscale in the model, an outcome that has been reported for the first time.

These findings were complemented by the interviews with the spouses/caregivers. The spouses worked under demanding conditions to keep their families functioning and in so doing reported feeling distressed. The main factors associated with their distress stemmed from problems experienced adapting to and building new structural, organisational and transactional patterns in the family. The spouse/caregiver's post brain injury role was often a great burden as they took on most, if not all, those household and family responsibilities that had been in the partner's domain, coping with going to work or submitting workers' compensation and pension claims, undertaking extra duties in and around the home, and incurring many additional expenses as a result of their spouses injury (e.g. medical expenses) at a time the family income was greatly reduced. And in addition to this, the deterioration in sexual relations, lack of empathy from the injured partner, poor social development, and abandonment from friends and relatives left the spouse/caregivers feeling alone, isolated and depressed about their situation. This data was reflective of spouses being trapped in a loss cycle because they lacked the resources to offset their losses. It is little wonder the level of distress was at caseness level for the majority (61%) of spouse/caregivers.

Importantly, the findings confirm the opinion of previous researchers (Gervasio and Kreutzer, 1997; Kreutzer et al., 1994a) that the elevated scores on the BSI subscales reflected a general construct of distress rather than diagnostic differentiation of various types of psychopathology (Slaughter et al., 1999). In this study the symptoms of distress experienced by relatives were a stress reaction to the threat or loss of family resources or attempts to replace resources. For instance, many of the spouses (and parents) reported psychotic and obsessive – compulsive symptoms at caseness level on the BSI. Inspection of the items on the subscales scales showed relatives were responding to items such as 'Something is going wrong with my mind,' 'Feeling blocked in getting things done,' 'Having difficulty making decisions' and 'Trouble concentrating,' which were all complaints reported by the spouses as they reflected on the challenges of keeping the family functioning, rather than necessarily being symptoms of psychopathology. Furthermore, high levels of anxiety, depression and hostility were reported and it may be tempting to conclude that the relatives were clinically depressed but further assessment with a structured diagnostic interview (e.g., DSM-IVR; American Psychiatric Association, 2000) would be required before any such definitive diagnoses could be made.

Despite the high levels of disrupted family functioning and psychological distress, the outcome for relatives was not always negative. Indeed, family functioning for some spouses

and parents was effective on all six dimensions of the FAD subscales, and the level of psychological distress was below caseness on the BSI subscales as well. This suggests that there are families who cope well despite severe TBI. The interviews showed that successful functioning occurred when the couples were able to support one another, were clear and direct in their communication on instrumental and affective issues, and were flexible in the face of change. Moreover, the couples tended not to view the disability as threatening or challenging to family life, and were able to discuss the problems of TBI openly, and the spouse/caregiver appreciated the partner's capabilities and encouraged him/her to play a role in the family. In two of these cases the couples also appreciated the need for personal development outside the home, and belief in God provided them with the strength to cope. This outcome was underscored by the behaviour of the injured partner, where even-tempered partners were easier to live with compared to injured partners with unpredictable, aggressive behaviour.

Clinical Implications and Future Research

Based on the findings from this study, there are a number of potential clinical directions that therapists could explore in their work with families, with the caveat that any such directions could only currently be accorded the status of practice options, and will await further research and testing before they can be upgraded to practice guidelines or standards (Cicerone et al., 2000). The findings suggest the need for professional intervention for dealing with disrupted family functioning (e.g., Perlesz et al., 1992). One of the themes elicited in the in-depth interviews was the problem of couples not communicating directly and clearly with each other. In many instances the spouse/caregiver was reluctant or even afraid to talk with the injured partner about instrumental or affective problems, given the potential for conflict. Subsequently, there was little gain for the spouse/caregiver in the relationship leaving him/her feeling distressed. Therefore, it may be important for therapists to facilitate open and honest communication between relatives on brain injury, family, and marital issues (Perlesz et al., 1992).

Relatives had difficulties in coming to terms with role functions post TBI, subsequently high levels of burden were frequently reported by spouse/caregivers. To the extent that this is a problem, Larøi (2003) has outlined ways in which therapists may actively assist in the redistribution of roles and responsibilities to compensate for functional impairments following TBI. In situations where relatives such as spouses are sole carers, further financial and practical assistance with instrumental problems may also be necessary (Hall et al., 1994).

Lack of personal development was another theme identified by family members interviewed in this study. In the current study, some of the spouses had put careers on hold and abandoned the pursuit of recreational activities altogether. There were a variety of reasons for this including: increased responsibilities in role functions; physical dependency; and egocentric behaviour by the person with brain injury. The findings suggest that supporting relatives in being able to pursue vocational or leisure interests independent of their supporting role with the person with TBI, may be of benefit in reducing carer distress. One of the barriers to in achieving such goals was the level of support required by many people with TBI, and within this context relatives have identified the lack of appropriate respite care options as a concern. However, the interviews also identified that some relatives found it

difficult to negotiate such arrangements with the person with TBI when it was available, and within this context it may be necessary for relatives to undergo assertiveness skills training in order to manage such situations.

Future research could test the model with a larger sample of relatives, which will enable comparisons between parents and spouses to be examined more closely. Moreover, gender differences should be tested in the model using path analytic techniques before generalisations can be made on family dynamics when a person has a severe TBI. Furthermore, the majority of participants were Australian with English speaking backgrounds. Therefore, it would be beneficial to study psychological distress and TBI with a more diverse population.

Limitations

There are several limitations in this study that should be understood when considering the findings. The parents and spouses interviewed represented intact families since discharge from rehabilitation, which means the sample has an inherent bias. The parents and spouses had remained together for many years after the injury, which means they had made some degree of adjustment to living with a relative with severe TBI, in comparison to families that have disengaged and gone their separate ways. Furthermore, this study was a cross-sectional design; subsequently a longitudinal design will be necessary for detecting and interpreting changes over time. Moreover, a control group would allow identification of the extent families with brain injury differ from families without a member with TBI. Within this context, it is not clear how applicable the US norms on the FAD are to the Australian context. Furthermore, the MMFF: "couples" (Bishop et al., 1987) interview was limited to spouse/caregivers; therefore, interpretation of the findings should be done with caution until findings from in-depth interviews are reported involving parents of adult children with severe TBI.

CONCLUSION

The findings of this descriptive correlational study generally supported the model which was based on COR theory and the McMaster Model of Family Functioning as a way of understanding psychological distress in parents and spouse/caregivers of relatives with severe TBI. This model helps clarify the complexity of the changes in the structure; organisation and transactional patterns that takes place in the family, which may better reflect the present state of knowledge of psychological distress in relatives following TBI. In addition, the model lends itself to further testing and refinement and comparison with alternative models that may encourage researchers in brain injury to adopt a more theory based approach to their research, which will increase the validity of their findings in the context of the study of stress.

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