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**Perception of Support Provided for People with Traumatic Brain  
Injury in relation to Caregiver Burden**

A thesis  
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### Abstract

This study explores caregiver perceptions of social supports provided for people with Traumatic Brain Injury (TBI) in relation to caregiver burden. Twenty-four people acting as primary caregivers of a person with TBI completed measures of social support and caregiver distress (Head Injury Behaviour Scale and a social support questionnaire developed specifically for this study). The domains assessed included the nature and number of treatment services utilized by the TBI person and caregivers' perceptions of these, the problems exhibited by the TBI person, and the distress experienced by the caregiver. Significant correlations were found between caregiver distress and the following variables: number of problems exhibited by the TBI person, change in caregiver employment status, helpfulness of treatment services for TBI person, and overall caregiver satisfaction. Regression analyses revealed that the number of problems exhibited by the TBI person and lack of helpfulness of treatment services were significant predictors of caregiver distress. These correlations and regressions were interpreted with respect to the buffering hypothesis and the Stress Appraisal Coping model (SAC). It was concluded that caregiver perception of social support rather than social support *per se*, is associated with caregiver distress, and that caregiver perception can buffer or attenuate caregiver distress. Methodological considerations and directions for future research are discussed.

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## **Formulation of Social Support**

Traumatic brain injury (TBI) constitutes a major public health problem as the leading cause of death and disability for individuals under 35 (Fletcher, Ewing-Cobbs, Francis, & Levin, 1995; Jacobs, 1988). An increase in the sophistication of medical technology means that people who would formerly have died of their injuries now survive, effectively increasing the number of survivors living with the aftermath of severe TBI.

Age and gender variables are associated with the occurrence of TBI. Children and the elderly are more likely to suffer damage through falls while other age groups, especially males aged 18-30 years, sustain more TBI in motor vehicle accidents (Lezak, 1995). It is unlikely that the incidence of TBI will decrease in the immediate future as the amount of traffic on our roads continues to rise (Hickey, O'Boyle, McGee, & McDonald, 1997). The implication of this is that these people face years of disability long after they are discharged from the hospital (Jennett, 1990) with massive human costs to the victim, family, as well as to the health care system (Bailey, 1989; McMordie & Barker, 1988).

Outcomes after TBI include cognitive deficits (memory and learning difficulty, impaired complex problem-solving, reduced information processing speed, impairment of language function, and lack of awareness of difficulties) and behavioural and emotional difficulties (lack of self-confidence, childish behaviour, decreased motivation, and irritability and aggression) (Leathem, Heath, & Woolley, 1996). The behavioural and emotional changes, which collectively constitute the changes in the patient's personality following injury (Brooks, 1991), cause families the greatest distress (Barry & Clark, 1992; Brooks, 1984, cited in

Curtiss, Klemz, & Vanderploeg, 2000; Brooks & Aughton, 1979; Eisner & Kreutzer, 1989; Knight, Devereux, & Godfrey, 1998; Oddy, Humphrey, & Uttley, 1978; Rutter, Chadwick, Shaffer, & Brown, 1980; Thomsen, 1974, 1984; Weddell, Oddy, & Jenkins, 1980). The cluster of difficulties associated with behavioural and emotional changes is chronic and persistent over time and is made more complex by lowered frustration tolerance and reduced capacity for self-control and regulation, as well as the mood fluctuations, disinhibition and loss of insight that results from frontal damage (Bowen, Tennant, Neumann, & Chamberlain, 2001; Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Brooks & McKinlay, 1983; Cavallo, Kay, & Ezrachi, 1992; Fahy, Irving, & Millac, 1967; Godfrey, Knight, & Bishara, 1991; Groom, Shaw, O'Connor, Howard, & Pickens, 1998; Leathem et al., 1996; Lezak, 1978; Livingstone, 1987; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Marsh, Kersel, Havill, & Sleigh, 1998; Maus-Clum & Ryan 1981; Oddy et al., 1978; Weddell et al., 1980). Studies at 3-12 months after injury (Marsh et al., 1998; McKinlay et al., 1981), two years after injury (Thomsen, 1974), five years after injury (Brooks et al., 1986), and six years after injury (Jacobs, 1983-1984) consistently report that psychosocial sequelae and changes in personality are the source of the greatest distress for family members. The data on families of the person with TBI shows that improvement in coping, morale, or other aspects of family functioning does not naturally occur (Brooks, 1991).

It is no wonder that TBI is often conceived as a "family affair" (Lezak, 1988), for TBI not only changes the life course of the person injured, but also results in significant change in the lives of family members (Wallace, Bogner, Corrigan, Clincott, Mysiw, & Fugate, 1998). Brooks (1991) points out that a

family constitutes more than its individual members and is better conceptualized as a system whereby all individuals are involved, and work towards both individual and group goals. TBI disrupts the balance of the system, exerting major impact not only on individual members, but the way in which the family works as a system.

The primary caregiver of a person with TBI is defined as someone who knew the patient prior to their TBI and who has had regular contact with them since their TBI (Marsh et al., 1998). Caregiver burden is defined as a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience. The impact of the burden is determined by the caregiver's perception of the burden, rather than the perception of other family members or healthcare providers (Stuckey, Neundorfer, & Smyth, 1996). Both the objective and subjective caregiver burdens warrant consideration. Objective burden constitutes the caregiver's tasks or activities. Subjective burden represents how caregivers feel about their roles (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

Many factors have been shown to affect the distress experienced by the primary caregiver of a person with TBI, including the gender of the carer (Sander, High, Hannay, & Sherrer, 1997), relationship between carer and person with TBI (Kreutzer, Gervasio, & Camplair, 1994), patient disability (Brooks, Campsie, Symington, & Beattie, 1987; Kreutzer, Gervasio, & Camplair, 1994i; Livingstone, Brooks, & Bond, 1985i; Livingstone, Brooks, & Bond, 1985ii; Sander et al., 1997; Allen, Linn, Gutierrez et al., 1994), subjective burden (Sander et al., 1997), financial strain (Moore, Stanbrook, & Peters, 1993), and satisfaction with social support (Sander et al., 1997). Social support is defined as both “instrumental”

(use of a social relationship as a means of achieving a goal, e.g., help with caring for a disabled relative) and “expressive” (affective aspects of relationships e.g., talking over a stressful situation with another person) (Douglas & Spellacy, 2000). The exact impact of social support as a factor in caregiver burden remains in its exploratory stages within research in New Zealand.

One study conducted in New Zealand has touched upon the subject (Marsh, Kersel, Havill, & Sleight, 1998). In this study primary caregivers completed questionnaires on the physical, cognitive, emotional, behavioural and social functioning of the person with TBI. At six months post injury, clinically significant levels of anxiety, depression, and impairment in social adjustment were evident for over a third of the caregivers. The presence of behavioural problems in the person with TBI had the most severe and pervasive impact of all aspects of the caregiver’s functioning. The social isolation and negative emotional behaviours experienced/exhibited by the person with TBI caused the greatest degree of stress for caregivers and their families, as did the impact that caregiving had on their personal health and free time. At one-year post injury clinically significant levels of anxiety and depression were evident for over a third of the caregivers, and a quarter of the caregivers reported poor adjustment. The TBI person’s emotional difficulties, in particular their anger, apathy and dependency, caused the greatest distress for caregivers. The physical impairment, number of behavioural problems, and social isolation of the person with TBI were the strongest predictors of caregiver burden.

This is a landmark study in the area of TBI as it suggests that social support is a significant factor contributing to caregiver burden. The conclusion to be drawn from the research is that caregivers with fewer social supports and/or

poorer quality social supports will have more negative psychological stress and health related problems.

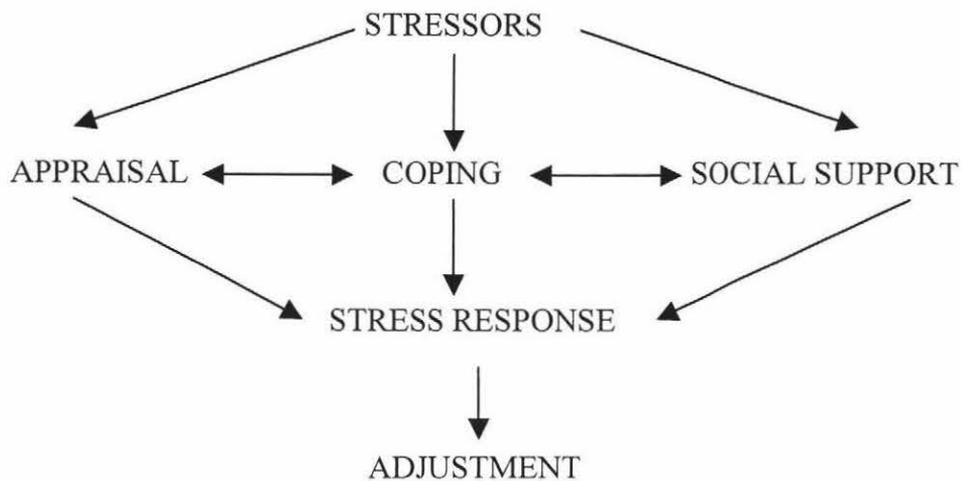
Models have been advanced within the field of TBI that can be used to explain the positive association between social support and wellbeing, such as that found by Marsh et al. (1998). The first posits an overall beneficial effect of support, irrespective of the occurrence of a stressful event. The second, the “buffering” hypothesis, suggests that support is related to wellbeing only for people under stress (Esterling, Kiecolt-Glaser, Bodnar, & Glaser, 1994; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993; Zarit, Reever, & Bach-Peterson, 1980). That is, social support buffers or attenuates the effects of stress. Both of these hypotheses predict that high levels of social support will be associated with better adjustment to chronic illness or disability.

However, it has been suggested that it is not social support *per se* that affects level of caregiver burden, but rather, the caregiver’s subjective *appraisal* of social support (Demellweek & O’Leary, 1998; Harris, Godfrey, Partridge, & Knight, 2001), as cognitive appraisal plays a role in determining emotion (Lazarus & Folkman, 1984). Lazarus and Folkman (1984), pioneers in the field of appraisal and emotion, define cognitive appraisal as “*the process of categorizing an encounter, its various facets, with respect to its significance for wellbeing. It is evaluative, focused on meaning and significance*” (p. 31).

Individual differences in stress reaction first gained recognition during World War II when it became clear that there was a need to better comprehend the behavior of soldiers under battle conditions (Janis, 1958). At the same time, Serle (1957) was investigating human and animal adaptation to stress at the physiological level. His investigation found that the relationship between

objective stress and physiological reactions was not strong. As a result, Lazarus began conceptualizing stress in respect to individual's interactions with their environments. In 1966 he advanced an integrative theoretical framework for conceptualizing the psychological factors in stress, that has since directed research in this area and generated stress management training (Godfrey, Knight, & Partridge, 1996). Lazarus' work has been particularly influential due to his placing stress within a coherent theoretical schema. While factors such as insight (Tyerman & Humphrey, 1984) and coping skills (Prigatano et al., 1986) have been identified as influencing emotional adjustment after TBI, these have not been placed within a comprehensive model (Godfrey et al., 1996) and thus have not been as dominant within the field.

Lazarus' (1966) Stress Appraisal Coping (SAC) model proposes that individuals experience emotional distress when they appraise their environmental demands as exceeding the personal and social coping resources available to them. This can lead to depression, low self-esteem, and anxiety. According to Harris et al. (2001), with caregivers these responses are mediated by (1) the carer's appraisal of the changes (threat perception), (2) the effectiveness of coping mechanisms that carers utilize, and (3) the amount of, and satisfaction with social and professional support received. Lazarus (1966) asserts that stress is most likely to develop under conditions of threat whereby important human values and goals are endangered, such as that experienced by caregiver of TBI when their pursuit of important pre-injury goals and values (employment, relationships, rest and recreation) may be at risk. This model is presented in the following diagram:



Harris et al. (2001).

In the SAC model, stressors are the demands placed on individuals as they live out their daily lives. Stress responses constitute the individual's negative reactions to the demands placed on them. Mediating variables influence the severity of the individual's stress responses by modifying the impact of the stressors, for example, social support (Godfrey et al., 1996). The SAC model differentiates two types of appraisal processes: primary appraisal and secondary appraisal. Primary appraisal refers to the individual's perception of the level of threat of a situation. Primary appraisal is not based on objective analysis, but a subjective inference that is partly governed by the person's psychological characteristics, such as their knowledge, beliefs, and expectations. In contrast, secondary appraisal governs the form of the coping response. The coping response selected from the person's range of skills is that which will solve the problem at minimal sacrifice. Godfrey et al. (1996) assert that the individual's perception of the level of threat (primary appraisal) will be a function of a constellation of situational, psychological and temporal factors, for example,

imminence. There are two important variables that determine threat: the significance of the variables endangered, and the person's beliefs in their self-efficacy, or ability to control the situation. In this regard, threat appraisal is strongly related to the individuals "psychology of self" (Godfrey et al., 1996).

In a preliminary study specific to the field of TBI, Godfrey et al. (1996) used the SAC model to examine emotional adjustment of people with TBI. They conceptualized the emotional adjustment of the individual with TBI as a response to neuropsychological symptoms and associated losses. The response, they said, is mediated by the individual's coping skills, social support, and appraisal. The authors found strong preliminary support for the model in regard to explaining the course of emotional dysfunction following TBI and the role of mediating variables.

A study by Knight, Devereux, and Godfrey (1997) also provides evidence for the SAC model, reporting that satisfaction with coping and social support were predictors of perceived burden, albeit with a sample of spouses of people with Multiple Sclerosis (MS).

Harris et al. (2001) used the SAC model in relation to caregiver burden. They found that the *number* of adverse effects on family members was the only significant stressor significantly related to depression. However, carer appraisal of adverse family effects mediated the relationship between stressor and depression, and carer perception of support effectiveness moderated the effect of adverse family effects on depression. Forty-six percent of the variance in caregiver depression was accounted for by the carer's appraisal of adverse family effects and interaction of adverse family effects and support effectiveness.

Although Harris et al. (2001) demonstrated caregiver *appraisal* of adverse family

effects and of support effectiveness to mediate and moderate caregiver depression respectively, their research conclusion seemed unrelated to caregiver appraisal. One of their concluding statements was that families must be supported as a whole throughout the rehabilitation of their relative with TBI and given ongoing professional and social support. This does not take into account that the provision of social support will only be beneficial if the intervention is perceived as useful by the carers.

Given that TBI and caregiver burden is such a problem within New Zealand, and social support has been identified as an interacting and predictive factor, the current study sought to examine in detail the impact of the caregiver's *perceptions* of social support in regard to their stress levels. In this regard, social support as an intervention is examined with reference to the buffering hypothesis and the SAC model. While there have been a number of static predictors identified as being predictive of caregiver burden, namely, the type of physical impairment, the number of behavioural problems, and social isolation (Marsh et al., 1998) the current exploratory study hypothesises a potentially more robust and dynamic predictor of caregiver burden. Specifically, it is hypothesised that there will be a progressively negative relationship between perceptions of social support as an intervention and caregiver burden levels and that this relationship will be independent of the static predictors of caregiver burden identified by Marsh et al. (1998). From a clinical perspective, perception, unlike its static counterparts, is an active process (Dagnan & Sandhu, 1999) and has the potential to be changed thus providing the caregiver(s) with the opportunity to decrease their burden levels through perhaps an untried targeted intervention, for example, Cognitive Therapy, that has a very strong evidence base (Lambert & Bergin, 1994). This

hypothesis provides further depth to the assertion made by New Zealand researcher's Harris et al. (2001) that decreasing caregiver burden levels is merely associated with increasing social support. Rather, it is formulated that decreasing caregiver burden levels also lies in the caregiver's perceptions and attitudes towards the social support intervention, which ultimately should be able to buffer or attenuate the effects of stress.

This study commences with a reformulation of social support, continues with a method section, and concludes with results and discussion sections.

## **Impact of TBI on Family Members' Lives**

### ***The Psychological Impact of TBI***

Very rarely will a TBI result in a welcomed and positive change in personality and family members will become much happier after the injury (Fahy, Irving, & Millac, 1967; Maus-Clum & Ryan, 1991; Sachs, 1985). Most commonly, the consequences are highly negative, as relatives are suddenly faced with the task of coping with a person very different from the one they knew prior to the injury (Knight et al., 1998) as well as facing major changes in family routine, housing conditions, financial status, and social and leisure activities (Wallace et al., 1998). This leads to stress, role change issues, and health problems (Leathem et al., 1996) that are unique to family members of people with TBI (Peters, Stambrook, Zubec, Moore, & Dubo, 1989; Rosenbaum & Najenson, 1976) and that tend not to diminish with time (Knight et al., 1998).

Family reactions to TBI are unique to that of other disabilities, simply because TBI is a disability unlike others. Spinal Cord Injury (SCI) can be viewed as the disability with the closest resemblance to TBI, because like TBI, the majority of SCI sufferers are male, disability is caused by sudden change to the Central Nervous System (CNS), lengthy hospital stays and separation from the family is required, and role change in the family is necessary (Florian, Katz, & Lahav, 1989). However, the functional and post-injury adjustment differences between TBI and SCI are profound, and highlight just how significant the consequences of TBI are.

In terms of functional differences, while the implications of SCI are mostly physical, the implications of TBI comprise a combination of physical, cognitive,

emotional, and behavioural deficits. As a result, TBI affects a larger number of activities and functions in different life domains, causing greater dependency on relatives (Groswasser, Kimchi, Stern, & Najenson, 1982, cited by Florian et al., 1989). TBI and SCI can also be differentiated in regard to coping with the injury. The reasoning is that adjustment can only occur if a new reality is emotionally accepted. Acceptance requires accurate perception of reality, correct judgment, and flexibility in thinking, these being mechanisms that people with TBI typically lack. More often, concrete and primitive defense mechanisms are used because the person with TBI cannot appraise the threatening aspects of a situation. This prevents insight into the new reality from occurring (Silberg, 1983, cited by Florian et al., 1989). Adjustment is also contingent upon matching the pre-injury self-image to the new reality. The cognitive skills necessary for this include the ability to analyze, the ability to produce higher order concepts, a flexible attention span, and the ability to understand sequential events in a series (Silberg, 1983, cited by Florian et al., 1989). As these abilities are commonly impaired in TBI (Brian, Green, Pratt, & Grigsby, 1984; Fitts, 1972; Rosenbaum, M., & Najenson, 1976), the process of adjustment is affected (Florian et al., 1989).

Essentially, the theoretical models that examine loss and disability emphasize that adjustment is a function of continuity between the past and the present in the life of the person and his/her family. With TBI continuity has been severed (Bray, 1978; Versluys, 1980; Florian et al., 1989). This has an acute impact on both the individual and the family. The consequence is high levels of stress and the continued existence of problems for the family years after injury (Florian et al., 1989). For example, Oddy et al. (1978) found that at one-year post injury, more than 50% of caregivers in the study experienced stress, with half of

these people experiencing serious stress. Similar findings were reported by McKinlay et al. (1981), and Brooks et al. (1986) who used the same population of caregivers and found that burden levels experienced by the families had increased between one and five years post injury.

Florian et al. (1989) has reviewed the responses characteristic of family members. These include, in order of frequency of occurrence, depression, denial, and anger and guilt respectively. Brooks (1991) adds that overprotection is also a common response of family members to TBI. Indeed, depression has been cited as the most common response to TBI for both sufferers and carers by many other authors (e.g., Brooks et al., 1987; Kreutzer et al, 1994i; Lezak, 1978; 1986; Linn, Allen, & Willer, 1994; Livingstone, 1987; Livingstone et al., 1985i; Maus-Clum & Ryan, 1981; Oddy et al., 1978; Olver, Ponsford, & Curran, 1996; Rosenbaum & Najenson, 1976; Tyerman & Humphrey, 1984; Wilkinson, Fisher, & Bromfield, 1989). For example, Linn et al. (1994) found that 73% of the 60 spouses in their study had mild elevations of depression. Douglas and Spellacy (2000) report a similar figure. They found that 60% of carers demonstrated significant symptoms of depression, with social support being a strong predictor of depression.

Lezak (1995) maintains that all relatives who live with a TBI person suffer from depression. She argues that the depression can be related to the emotional burden of caring for the relative, or due to the mood fluctuations of the person with TBI. Lezak (1978) states that family members' feeling trapped and hopeless will suffer at least two episodes of deep depression, show suicidal ideation, or abuse alcohol or drugs. In support, Panting and Merry (1972) found 61% of

relatives of people with TBI were long-term users of tranquilizers or sleeping pills.

The persistence of depression is significant. High levels of psychosocial disability in families have been observed as late as 10-15 years (Rappaport, Herrero-Backe, Rappaport, & Winterfield, 1989; Thomsen, 1984). The more severe the injury, the greater the subjective burden for the relative, although some argue that this only occurs up to a Post Traumatic Amnesia (PTA) of approximately two weeks. Beyond this, increasing severity of injury has little more effect (Brooks et al., 1986; 1987; Brooks & McKinlay, 1983; McKinlay & Brooks, 1981; Peters, Stambook, Moore, & Esses, 1990).

Thomsen (1974) found that while level of disability had no relationship to depression for those with TBI, it was a significant predictor of depression for carers. This is consistent with previous research regarding associations between the neurobehavioral function and carer stress (Oddy et al., 1978), burden (Brooks et al., 1987; Livingstone et al., 1985i; Allen et al., 1994) and psychological distress (Kreutzer, Serio, & Berquist, 1994ii) as well as marital adjustment (Douglas & Spellacy, 2000) and family functioning.

Another frequent response by family members to TBI is denial, a reaction that is often described as the opposite of depression (Florian et al., 1989; Hendryx, 1989; Lezak, 1986, McLaughlin & Schaffer, 1985; Parmelee, Kowatch, Sellman, & Davidow, 1989; Stern, Sazbon, & Becker, 1988). Brooks (1991) conceptualizes denial as a defense mechanism. That is, an unacceptable reality is replaced with a more desirable situation. Brooks (1991) views denial is a coping reaction that according to the situation and its duration can be very effective indeed.

Romano (1974) studied families of people with severe TBI over periods of seven months to four years after TBI and found that the family's earliest response was denial, and that there was relatively no movement through to the other stages of the grief model (Kubler-Ross, 1969). In addition, unrealistic expectations were also present, and when expectations did not come to fruition, anger towards the treatment team surfaced. According to Lezak (1978), unrealistic expectations by family members are related to: family members having difficulty evaluating changes that the person with TBI has undergone; denial of the history of the TBI and seeing improvements where none exist because the acknowledgment of no improvement is likened to the rejection of the person with TBI; failure to comprehend the implications of TBI; the initial improvement reinforcing hope that pre-injury functioning will return; the medical team being cautious over its initial prognosis therefore the message conveyed being ambiguous; and the patient surviving the injury suggesting to the family that given one miracle has occurred another can be expected, especially given reports in the media of breakthroughs in scientific medicine (Stern et al., 1988).

Lezak (1986) presents a model of the evolution of family reactions to TBI. There are six stages of adjustment, each characterized by distinct perceptions of the person with TBI, expectations for recovery, and family reactions. In the first few weeks post injury, the family is likely to be thankful for the patient's survival. The patient may be viewed as challenging but full recovery is expected within the first year. The family may become confused and anxious 2-9 months after injury when physical recovery begins to slow. Full recovery is still expected, but recovery rates lower than initially expected are attributed to the patient's uncooperativeness and lack of motivation. In the later stages of injury,

approximately nine months post-trauma, the family develops a relatively stable view of the patient as difficult and dependent. Expectations of improvement diminish, and this is accompanied by feelings of depression and a mourning process. Only in the final stages is the family likely to begin accepting that the patient's disabilities are to be life-long (Lezak, 1986; Maus-Clum & Ryan 1981; Romano, 1974). Underlying this model is that unrealistic optimistic expectations worsen the family stress over and above that associated with the TBI person's altered behaviour.

Another adverse reaction common among family members is anger (De Pompei, Zarski, & Hall, 1988; Lezak, 1978; Stern et al., 1988) and guilt (Gronwall, Wrightson, & Waddell, 1990; Lezak, 1988; McKinlay & Hickox, 1988). A summary of the literature reveals five common situations in which anger and/or guilt can manifest. The first of these is when caregivers perceive the TBI person's problem behaviour as a reflection of their inadequacies as caregivers. The second is when the caregiver believes that the person with TBI is not making enough effort to improve his/her behaviour. Thirdly, a circle of anger can be generated through the aggressive behaviour of the person with TBI creating feelings of anger and revenge, leading to feelings of guilt at having feelings about someone who has obviously suffered so much (Brooks, 1991; Lezak, 1986). Fourthly, anger may occur as a result of caregivers finding themselves resentful about the toll on their lives, and insight into this reaction succeeding only in making them feel guilty about their feelings (Kasuya et al., 2000). Finally, caregivers may become angry at physicians and therapists when recovery begins to decelerate (Brooks, 1991).

Overprotection frequently occurs after TBI (Guth, 1988, cited by Brooks, 1991). It can destroy progress accomplished by therapeutic staff, particularly when the TBI person achieves independence in some areas of functioning while in active rehabilitation, and then loses these achievements on returning home. However, it may well be that family members do not have the time to supervise, guide and prompt, and as a result, simply do things for the injured person (Brooks, 1991).

### ***The Impact of Kinship Relationship on Burden***

According to Lezak (1988), the nature and severity of problems will differ according to each family as a function of premorbid cohesiveness, family attitudes about illness and responsibility, and financial and social supports. It will also differ among family members, with the person responsible for being primary caregiver experiencing more of the burden.

Evidence suggests that wives have more difficulties in dealing with the consequences of TBI than other family members, as their relationship is more profoundly altered (Brooks, 1984, cited by Brooks, 1991; Kozloff, 1987; Lezak, 1988; Silberg, 1983, cited by Florian et al., 1989; Thomsen, 1984; Thomsen, 1974; Serio, Kreutzer, & Witol, 1997). Predominantly, this is as a result of the difficulties wives have in adjusting to one of the main features of posttraumatic behaviour: the regressive behaviour of their spouse, which is childish and inappropriate (Florian et al., 1989).

Regressive behaviour is more difficult for the wife to deal with as it represents a new feature for them. In comparison, mothers have previously dealt with it and find it easier to accept the changes. Childish dependency is an

inherent part of the parent-child relationship, even though it decreases with age (Florian et al., 1989).

The physical care required in caring for a person with TBI also more greatly impacts on the wife (Panting & Merry, 1972). Although parents are older than spouses, two parents can share the burden and support and relieve each other in the physical care of their child. Conversely, the wife is isolated and has to cope with this burden on her own, and may also have other children to look after (Maus-Clum & Ryan, 1981; Panting & Merry, 1972; Rosenbaum & Najenson, 1976).

Moreover, major friction may be generated as the parent tries to overprotect their injured child and the spouse tries to promote independence (Rosenbaum & Najenson, 1976). Again, this will cause greater burden for the wife, who has to contest the mother, and may lose her as a source of support in the process. The mother has less to lose in this situation as she still has her own partner to whom she can turn to for support.

Maus-Clum and Ryan (1981) measured the following sources of stress response in wives and mothers: frustration, irritability, depression, decline in social activities, anger, reduction in personal time, and lack of economic security. In all categories except frustration, wives reported more stress than mothers. Over time however, Thomsen (1984) found that the spouses achieved a more realistic perception than parents. Thomsen (1984) suggests that the limited insight may explain the parents' higher frustration levels. That is, the parents may have had unrealistic expectations of recovery. When expectations were not met, they felt frustration (Florian et al., 1989). Thomsen (1984) found that even as late as 10-15 years after injury, mothers were still denying the impact of the TBI.

The wife/mother scenario in the case of TBI provides support to the buffering hypothesis and SAC model. With TBI, the wife, who is partner-less in her plight to care for her husband, is likely to have a poorer perception of social support, and be affected by greater stress than the mother, who (generally) has a husband with whom to share the burden. Essentially, it is the person who has a positive perception and attitude towards their social support, who has a buffer to mitigate the effects of stress and caregiver burnout.

In terms of pediatric TBI, Barry and Clark (1992) has noted that families of child patients have a more difficult time during in-patient rehabilitation than families of adult patients. They claim that the parent's sense of responsibility over the child makes it harder for them to leave their child at the 'mercy' of a team of professionals at a point in time when the child is most vulnerable.

Research strongly shows that having a child suffer a chronic illness (Eisner, 1993) or congenital physical disability (Beresford, 1994) puts parents at risk of developing psychological problems. One study followed up children who had sustained a severe injury (including but not limited to TBI) and were admitted to a pediatric trauma unit over a one-year period. The percentage of maternal psychological disorders increased markedly from premorbid to levels of 16% to about 59% while the child was in hospital and declined slowly over the following year to about 41%.

Results from exploratory research suggest that the level of maternal psychological distress is higher after the child has suffered moderate to severe TBI compared to an orthopedic injury (Taylor et al., 1995). Osberg, Brooke, Baryza, Rowe, Lash, and Kahn (1997) found that parents of children with TBI had

difficulty maintaining regular work schedules and injury-related financial problems were very common.

Siblings too are affected. Orsillo, McCaffrey, and Fisher (1993) found that 83% of siblings in their study had levels of psychological distress that required clinical intervention. Wade, Drotar, Taylor, and Stancin (1995) found that 46% of siblings in their study had developed some emotional problems, school problems, or aggressive personality problems. Sokol et al. (1996) claims that siblings may feel neglected by their parents who devote all attention to the child with TBI. They may have extra responsibilities placed on them, and might feel burdened with an unrealistic expectation to be tolerant of the child with TBI. The situation of the sibling may mean that further conflict occurs within the family (Brooks, 1991).

### ***The Effect of TBI on Relationships***

The frequency of problems in TBI sexual relationships is high: three out of four rehabilitants report problems in sexual relationships (Price, 1985). This problem is more related to the changes in personality secondary to the effects of TBI (Lezak, 1976; 1978; McKinlay et al., 1981; Rosenbaum & Najenson, 1976; Wood, 1984, cited by Florian et al., 1989). That is, husbands may engage in regressive behaviours, including tactless attempts at initiating behaviour, discussions with sexual overtones, inappropriate touching, and in extreme cases, masturbation and exposure in public (Lezak, 1995; Wood, 1984, cited by Florian et al., 1989). These behaviours, and the fact that the wife perceives the husband as a changed and different person, may mean that wives dislike being touched by their husbands even if they are able to perform sexually (Brooks, 1991;

Rosenbaum & Najenson, 1976). The person with TBI may also fail to meet the spouse's sexual and affectional needs as a result of having lost the capacity for sensitive and reciprocal intimacy (Lezak, 1978, 1995).

It seems that problems with sexual relationships do not persist with Spinal Cord Injury (SCI) as they do with TBI. Vargo (1984) reported that while SCI couples experienced problems with sexual relationships after the initial injury, sex did not continue to be an area of frustration for the wives. Husbands with SCI were able to compensate for inability to perform sexually with intimacy and togetherness. With TBI, regressive behaviour compromises the capacity of the husband to problem solve solutions with the wife and act as an equal in the relationship.

Overall in fact, SCI relationships are more amenable to repair than TBI relationships. Bray (1978) and Vargo (1984) examined impact of disability for SCI wives in the short term, and long term. The first stage of adjustment with SCI was characterized by separation of the couple in which each spouse worked through the process individually. At this point the wives were subject to anxiety and pressure. Over time, open communication and the pre-injury levels of intimacy enabled conciliation and the meeting of personal and interpersonal needs. Other authors have also cited the importance of reciprocity, intimacy, and open communication in the recovery from a SCI (Simmons & Ball, 1984; Trieschmann, 1981). These elements are often missing in relationships after TBI.

TBI also affects the person's ability to help with childcare (Brooks, 1991; Jacobs, 1983-1984). This has financial and emotional consequences. Financially, the supervising family member may have to give up a job or full time education to look after the children in the family (Brooks, 1991; Jacobs, 1988; Serio et al.,

1997). Emotionally, the person with TBI may have a decreased role in parenting in turn meaning that they have less to do with the children. A lack of a father figure for identification not only hurts the children, but is worrisome for the wife, adding to the burden (Rosenbaum & Najenson, 1976).

Lezak (1978) notes that not only do many husbands with TBI take no responsibility for the children, they compete with the children for the wife's love and attention. The father may also show jealousy towards the children as their abilities surpass their own. The implication of this may be that the children show even greater dependency on the mother, out of fear of their father. The distress experienced by the children may also place the wife in a lose-lose situation. The wife may abandon the husband who is dependent on her for the sake of the children, but come across moral problems, or economic problems. Remaining with the husband however, may constitute passive neglect of the children. It appears that children of fathers with TBI are a high-risk group that may require specific intervention.

Lezak (1978, 1987, 1988) outlines the loneliness and social isolation experienced by the spouse of a person with TBI. They are caught in a double bind as they no longer have a partner with whom they can enjoy social activities, and cannot start a new relationship with another partner as they are still married. Loneliness may also result from the wife having to take on responsibility both within the family and within society, with no support from the husband (Lezak 1978; Rosenbaum & Najenson, 1976). Essentially, the resources for mutual decision-making are lacking or limited such that the person cannot contribute to new balance and adjustment, but moreover, their lack will exacerbate the feelings of loss and maladjustment. In his study Brooks (1991) found that wives perceived

the TBI as a social handicap. They reported a number of major role shifts including being a sexual partner to the husband, which they rated as less important, and handling family matters outside the home, which they rated as more important (Brooks, 1991).

The wives of people with SCI also retain the benefits of a partner who can advise and provide emotional support, even though physically they cannot always be involved. Essentially, with respect to the buffering hypothesis and SAC model, these wives have a husband who is able to compensate for the physical consequences of SCI, and accordingly, are more likely to foster a perception that they provide positive support, attenuating stress. In this regard, probably one of the greatest problems faced by wives of people with TBI is lack of support they receive from their husband (Florian et al., 1989).

For the wives of people with TBI, the life changes one year after TBI are very marked and negative, with fewer social activities than prior to injury, and social contacts significantly diminished (Kozloff, 1987; Oddy & Humphrey, 1980). Mood is considerably reduced compared with wives of SCI patients and non-clinical control wives (Brooks, 1991). It is not surprising that at six years post injury, there is a high incidence of marital breakdown. Based on Glasgow Outcome Scale (Jennett & Bond, 1975), it was found that for people with good recovery, 42% of pre-trauma marriages broke down, for those with moderate disability, 64% of marriages broke down, and for those with severe disability, 62% broke down (Tate, Lulham, Broe, Strettlles, & Pfaff, 1989). Anderson-Parente, Dicesare, and Parente (1990) found that two-thirds of TBI marriages had broken down and resulted in divorce within two years post-injury.

Moore et al. (1991) assessed the coping behaviours of wives of men who had sustained TBI, including the use of resources internal to (for example, cognitively reframing family problems), and resources external to the family (for example, seeking respite care). A cluster-analysis found three distinct groups (high, medium, and low) based upon the frequency of coping behaviour used. The high-use group expressed greater overall marital adjustment, whereas the low-use group reported greater sexual intimacy. The groups only differed in regard to age of the survivor, with the low-use group being youngest and the high-use group being oldest. The data suggests that attempting to cope actively with the effects of TBI may help to sustain satisfaction within the marital relationship. This may be because coping actively reflects self-generated initiative, and people are likely to have a more positive perception of support that they obtain from their own efforts.

Kosciulek, McCubbin, & McCubbin, (1993) suggested that families can cope with TBI in four ways:

1. Engage in direct action to remove the demands created by TBI;
2. Engage in direct action to acquire resources not already available;
3. Manage tension that results from the TBI-rated strains; and,
4. Cognitively reappraise or reframe the situation to give it less negative valence.

Again, this appears to support the buffering and SAC model, especially in regard to point four, which suggests that cognitively restructuring the situation will result in a more positive outlook. In their study, Minnes, Graffi, Nolte, Carlson, and Harrick (2000) also found that reframing and seeking spiritual support constituted coping strategies useful in stress reduction. A decrease in

caregiver burden may require changing the perception of the support intervention available.

Overall, the research literature suggests that the nature of the caregiver's relationship with the survivor should be taken into account when examining the impact of TBI-related stress (Curtiss et al., 2000; Gervasio & Kreutzer, 1997; Mauss-Clum & Ryan, 1981; Perlesz, Kinsella, & Crowe, 2000). TBI is a double blow to a wife, who not only loses a partner and a support source, but inherits a dependent. In this sense she is left with less coping resources but greater responsibility. Her levels of burden and burnout are likely to be very elevated.

## **The Social Impact of TBI**

### ***Social Isolation***

In families where there is a relative with a disability, when the physical injuries stabilize and the family reaches an understanding of the implications of the condition, the families' social contacts gradually improve. In families where there is a member with TBI, there is an opposite effect whereby families socially withdraw at this stage and conflict and tension materialize (Florian et al., 1989). Results of studies show family and social maladjustment emerging at 3-6 months after the injury, then stabilizing, but generally remaining poor (Livingstone et al., 1985i; Oddy, et al., 1978; Weddell et al., 1980).

Lezak (1978) maintains that social withdrawal occurs because families rarely go out as a result of the need to supervise the person with TBI. In addition, they rarely invite others to their home out of fear that the person with TBI might embarrass them. It is possible that the reduction in social activities is also due to denial of the situation. Essentially, society is critical and their reactions reflect the status of the person with TBI. In limiting social contact, families avoid facing up to the denial and other people's discouraging views of the person with TBI (Romano, 1974).

It also appears that social isolation occurs because of the dependency people with TBI have on their families. Kozloff (1987) examined social network size and density after TBI. What stood out was that with increasing time, the size of the network decreased and its density increased. That is, the number of social contacts reduced, and the only people maintaining lasting relationships were family members, this increasing the density of network as fewer unrelated people

interacted with the TBI person. Essentially, patients depended primarily on their next of kin for instrumental and emotional support. The ultimate consequences of greater dependency on the family were social isolation and conflict reemerging within the family. Similar findings are reported by Thomsen (1984), Elsass and Kinsella (1987), Marsh, Knight, and Godfrey (1990), and Marsh, Kersel, Havill and Sleigh (2002), who found that social isolation increased over time, as did the distress of caregivers. Thomsen (1974) found that additionally, over time members of the extended family spent less time with the family of the person with TBI, this succeeding only in isolating and burdening the immediate family. Moore et al. (1993) demonstrated lack of money as being a cause of greater dependency on family. That is, a lack of finances prevented the TBI person from pursuing desired activities, in turn increasing social isolation and reducing social contact, frustrating family and marital relationships.

Thomsen (1974) has shown exactly how many families can expect to be burdened by a dependent family member with TBI. She found that only 8% of 50 people with TBI were able to go back to their job between 12 and 70 months after the injury. For 72% returning to work, even sheltered employment, was not an option. These people remained fully dependent for their most fundamental needs. Eighty-four percent were affected by significant emotional and behavioural problems that impacted negatively on the daily routine of the family. Carers expressed a strong need for the provision of activity programmes for TBI adults, and education programmes for the public. Essentially, carers wanted their injured relative to become involved in something in the community.

Douglas and Spellacy (2000) examined both instrumental and expressive social support and their respective roles in affecting post-injury depressive

symptoms in a sample of Australian TBI patients and family members. The support items that received the highest mean rating for frequency of problems were too many demands on your time, having too many responsibilities, having too little leisure time, not seeing people you feel close to, not having a satisfactory sex life, and not having enough money. More than half of the carers (60%) were classified as showing significant symptoms of depression.

This seems to indicate that those people with better mood are those that have an ally with whom they can express their feelings and problems. Put in the context of the buffering hypothesis, social support provides family members with a coping resource useful in buffering against the stressors they are experiencing (Kosciulek, 1993; Pelletier, Alfano, Neilson & Fink, 1994). However again, the SAC model has to be taken into account, as it is only possible to react to stressor if it is perceived negatively. As such caregiver's subjective *appraisal* of social support must also come into play (Harris et al., 2001).

Using the SAC model, Harris et al. (2001) found that the *number* of adverse effects on family members was the only significant stressor significantly related to depression. It was not the social and behavioural changes exhibited by those with TBI that concerned caregivers, but rather, the effect that caregivers perceived that these had on other members of the household. Alfano et al. (1994) also found subjective perception to have a role in burden. They demonstrated that greater perceived psychosocial dysfunction and stress were associated with greater emotional distress for family members. In studying the spouses of people with Multiple Sclerosis (MS), Knight et al. (1997) found that burden was related to the carer's appraisal of the symptoms, perceived social support, and satisfaction with

coping. These results indicate that cognitive-behavioural strategies would be appropriate for use in these groups.

Pelletier et al. (1994) also found that an internal locus of control (believing that reinforcements are contingent upon one's own actions rather than due to luck or fate – external locus of control) (Berzins & Ross, 1973) and greater social support from friends, (not other family members), was significantly correlated with lower levels of perceived stress and better psychological health (Alfano et al. 1994; Neilson, Alfano, & Fink, 1991).

Recent research in Australia, (Stebbins & Leung, 1998) concluded that family needs increased from the need for predominantly medical and professional support during the two year post injury period, to include those based around community support, caregiver support, family support, financial resource, and health information at later stages. Over time, the needs rated as important by carers increased in number and type. This is because family carers faced an increasing number of problems with continued time since injury. In contrast, the number of met needs decreased significantly, leaving carers feeling isolated, misunderstood, and generally without support (Kreutzer, Serio, & Berquist, 1994). In their study, Moules and Chandler (1999) found that carers with a higher number of unmet needs had corresponding higher levels of psychiatric morbidity, and perceived lower quality of life. They concluded with the recommendation that researchers explore the hypothesis that providing an increased level of emotional and instrumental support could reduce psychiatric morbidity and increase quality of life.

What is argued in this study is that the type of physical impairment, the number of behavioural problems, and social isolation are static predictors of

burden. As such, caregiver feelings of being social isolated, misunderstood, and without support cannot be due to a relative increase or decrease in these variables. What remains is perception of social support, which is a dynamic variable that can change over time. In this regard, unmet needs may in fact be related to a change in the primary caregiver's perception over time of the effectiveness of social support offered (Sinnakaruppan & Williams, 2001).

Overall, the work of Harris et al. (2001) nicely depicts that caregiver appraisal of stressors is a prerequisite to experiencing depression. Their data highlights the importance of supporting families as a whole in the rehabilitation of persons with TBI in regard to families' perception of treatment. Essentially, family members deserve help in their own right, and not simply help that is a by-product of the rehabilitation of the person with TBI (Florian et al., 1989). The type of help required may be a cognitive intervention that targets subjective perception and brings it into congruence with objective reality.

## Summary

In many rehabilitation settings, the family is used as a resource for promoting the recovery of the person with TBI. However, mounting evidence suggests that family members in their own right are at high-risk for developing psychological, emotional and social difficulties. TBI exerts an effect across the entire family group, affecting both the health of family members and the quality of care they deliver. Ultimately, family members must be provided with adequate care in order that they do not become overburdened to the point that they are unable to provide the long-term care that the family member with TBI requires.

Research shows that the type of physical impairment, the number of behavioural problems, kinship relationship, and social isolation all impact on caregiver burden. To date, even authors who have found evidence to suggest that caregiver appraisal can mediate caregiver depression (Harris et al, 2001) argue that it is the provision of adequate support for family members that can mitigate the long-term psychological distress.

The current study adds an extra dimension to other New Zealand research in that it hypothesises that increasing social support alone will not decrease caregiver burden levels. Rather, it is argued that decreasing caregiver burden levels ultimately involves changing caregiver perceptions and attitudes towards the social support intervention. This is because according to the SAC model, what mediates social support and caregiver burden is the caregiver's subjective perception of the effectiveness of social support. It is therefore the subjective perception of social support that can buffer or attenuate stress. In order to decrease caregiver burden, intervention such as Cognitive Therapy may be needed

to bring the subjective perception of social support and the actual objective level of social support into congruence.

Despite the fact that family members frequently bear the long-term daily task of caring for the patient, their perception of the support that they receive in the New Zealand context is currently unclear. Therefore the principal aim of this study was to investigate the correlation between caregiver's perception of the support offered to them in New Zealand.

Accordingly, the following three hypotheses were posited:

- The relationship between social support and caregiver burden is mediated by the subjective appraisal of the effectiveness of that social support and is capable of buffering or attenuating against caregiver burden distress levels. Caregivers who are satisfied with the support provided will have decreased burden levels compared to caregivers who are dissatisfied with the support provided
- Treatment non-completion is positively related to increased caregiver burden levels.
- Number of social supports is not related to caregiver burden. That is, the key indicator of social support is not number, but perception of effectiveness of that support.

To clarify, this study does not attempt to evaluate the quality of care/social support received, rather it evaluates caregivers' perception of that support independent of the quality of the care provided. The research premise is that client perceptions, independent of quality, is a significant factor with respect to caregiver burden.

A questionnaire (the Social Support Questionnaire; SSQ) developed specifically for the current study, and the Head Injury Behaviour Scale (HIBS) (Smith & Godfrey, 1995) were employed to test the three hypotheses in the following ways:

The first hypothesis stated that the relationship between social support and caregiver burden would be mediated by the subjective appraisal of the effectiveness of that social support and that subjective appraisal of social support would be capable of buffering or attenuating against caregiver burden distress levels. Perception of social support was tested by the following SSQ items:

*“Was/is the specialised treatment service helpful for the person with the brain injury that you are close to? “Was/is the specialised treatment service provided for the person you are close to helpful to you in terms of assisting your role as caregiver?”; “Was/is the specialised treatment service provided for the person you are close to helpful to you in terms of your own wellbeing?”; and questions 1-6 on page two of the SSQ. By correlating perception of social support with level of distress, as measured by the HIBS, the first hypothesis could be tested.*

The second hypothesis stated that treatment non-completion would be positively related to increased caregiver burden levels. As this study is exploratory, the nature of treatment noncompletion was not sought (i.e., whether due to reasons such as the caregiver perceiving the intervention as ineffective or the person with TBI refusing to complete). However, it was believed that treatment noncompletion would add to burden, as it would constitute the loss of a social support intervention. The SSQ tested treatment noncompletion with the question: *“Did the person you are close to complete the specialised treatment service (please answer N/A if treatment is ongoing)?”* By correlating treatment

noncompletion with level of distress as measured by the HIBS, and the question on page two of the SSQ "*If the person that you are close to did not complete the specialised treatment service(s), overall, how much did this distress you?*" it was possible to evaluate whether treatment noncompletion was related to caregiver burden.

The third hypothesis stated that number of social support would not be related to caregiver burden, as the key indicator of social support is not number, but perception of effectiveness of that support. For this hypothesis to be tested an actual/objective measure of the social support interventions received needed to be obtained. This information was elicited by the SSQ item: "*Has the person that you care for received specialised treatment services from any of the following?*". By relating actual social support received to caregiver distress level, as measured by the HIBS, the relationship between objective social support and caregiver burden could be established. The significance of perception of social support could then be calculated by comparing actual social support received and caregiver burden with perception of social support and caregiver burden.

## Method

### Participants

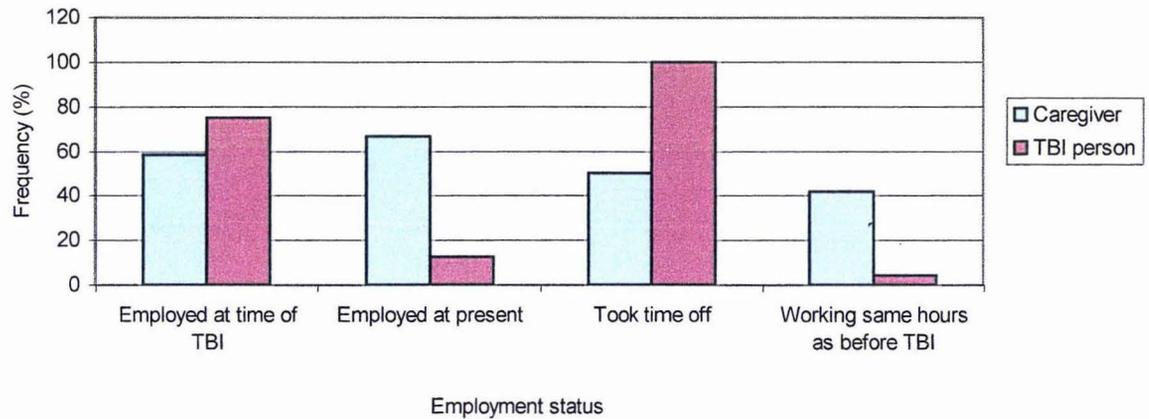
Participants were primary caregiver's of TBI clients attending various rehabilitation services in the Auckland, Waikato, New Plymouth, and Manawatu regions. A primary caregiver is defined as someone who knew the patient prior to their TBI and who has had regular contact with them since their TBI. Of the people invited to participate, a total of 24 agreed.

Of the caregivers, 22 (91.7%) were female and 2 (8.3%) were male. The mean age category of the caregiver was 46-55 years (range = 26-75 years). Eleven (45.8%) were the mother, 1 (4.2%) was the father, 6 (25%) were the sibling, 5 (20.8%) spouse/partner, and 1 (4.2%) was a friend. A total of 14 (58.3%) caregivers were employed/studying at the time of the TBI, and 16 (66.7%) were employed/studying after the TBI. Of those employed, 10 (41.7%) took time off work. Of those still employed at the time of assessment, 10 (71%) were working the same hours as before the TBI (see Figure 1). This demographic data is presented in Table 1.

Nine (37.56%) of the TBI patients were female and 15 (62.5%) were male. The mean age category of the people with TBI was 36-34 years (range = 26-65 years). The mean time post injury was between 6 years and a day to 10 years (range = 6 months to more than 15 years). The average length of coma range was 8 days to 1 month (range = less than 7 days to still unconscious). Of the 18 (75%) of TBI people employed/studying at the time of TBI, 3 (12.5%) remained employed. Only one (4.2%) of these people was still working the same hours after the TBI as before the TBI. This demographic data is also presented in Table 1 and Figure 1.

Table 1  
*Demographic Characteristics of the Caregivers and People with TBI*

Demographic Characteristic	Frequency (%) for Caregivers	Frequency (%) for TBI people
Female	22 (91.7)	9 (37.56)
Male	2 ( 8.3)	15 (62.5)
26-35 years	1 ( 4.2)	7 (29.2)
36-45 years	7 (29.2)	2 ( 8.3)
46-55 years	9 (37.5)	8 (33.3)
56-65 years	5 (20.8)	5 (20.8)
66-75 years	2 ( 8.3)	2 ( 8.4)
Mother	11 (45.8)	-
Father	1 ( 4.2)	-
Sibling	6 (25)	-
Spouse/Partner	5 (20.8)	-
Friend	1 ( 4.2)	-
Employed/Studying at time of TBI	14 (58.3)	18 (75)
Employed/Studying after TBI	16 (66.7)	3 (12.5)
Took time off work	10 (41.7)	24 (100)
Work same hours as before TBI	10 (71)	1 ( 4.2)
Time comatose: less than 7 days	-	9 ( 42.9)
8 days – 1 mth	-	8 ( 38)
29 days – 6 mths	-	2 ( 9.5)
6 mths, 1day – 1 year	-	1 ( 4.8)
Still in coma	-	1 ( 4.8)
Time in hospital:less than 7 days	-	1 ( 4.5)
8 days – 1 mth	-	3 (13.6)
29 days – 6 mths	-	12 (54.6)
6 mths, 1day – 1 year	-	4 (18.2)
Still in coma	-	2 ( 9.1)



**Figure 1:** Relationship between employment at time of TBI and employment at present for TBI person and caregiver

## **Measures**

Caregivers completed three self-report questionnaires: a demographic questionnaire (see Appendix A), a questionnaire on social support developed specifically for the study (the Social Support Questionnaire; SSQ) (see Appendix B), and the Head Injury Behaviour Rating Scale (HIBS; Caregiver Version) (see Appendix C).

The demographic questionnaire was designed simply to obtain demographic information on the sample employed. The SSQ and HIBS were designed to test the three hypotheses.

### ***The Social Support Questionnaire***

The SSQ is designed to elicit two types of information: firstly, the actual or objective number of social support interventions provided for the person with TBI, and secondly, the caregiver's subjective appraisal of social support interventions provided. The SSQ is divided into two parts, the first generates

information regarding the specific social support interventions received and requires the participant only to tick the relevant boxes (Yes, No, or N/A). The second part of the SSQ yields information regarding the treatment services received overall across professions, and requires the respondent to respond to five Likert scale questions (overall helpfulness were treatment services for the TBI person, caregiving role, and caregiver wellbeing; overall level of satisfaction; distress at treatment noncompletion) two yes/no questions regarding whether there were any services the caregiver received for themselves, or any services they would have liked the TBI person to receive, and one open question regarding what services the caregiver would have liked to have seen provided for the TBI person.

### ***The Head Injury Behaviour Scale***

The HIBS is a 20-item questionnaire that requires caregivers to identify changes in the TBI patient's behaviour since the injury, and indicate how much distress these changes have caused for them. Degree of distress is rated on a 4-point Likert scale from 1 (no distress) to 4 (severe distress) (Godfrey, Harnett, Knight, Marsh, Kersel, Partridge, & Robertson, 2003).

The 20 problems described in the HIBS were identified from a survey of the literature on personality changes following TBI (Godfrey, Marsh, & Partridge, 1987). A principal component analysis conducted on the HIBS revealed a two-factor solution with 10 items loading on each factor, suggesting that the HIBS assesses two constructs. The first subscale, Emotional Regulation, assesses behaviours reflecting impaired emotional control, occurring during interactions with caregivers. The second subscale, Behavioural Regulation, assesses problems

typical of dysexecutive syndrome, but which carry less negative valence for caregivers. Both subscales were found to have good internal consistency.

A number of studies have provided support for the psychometric properties of the HIBS. Godfrey, Partridge, Knight and Bishara (1993) conducted a study that examined self-awareness following TBI. HIBS ratings were obtained from 66 persons with TBI and their carers. Reliability of the HIBS distress ratings for the sample was strong for both self-report ( $\alpha = 0.93$ ) and other report ( $\alpha = 0.87$ ). Likewise, a study examining self-awareness following TBI was conducted by Fleming, Strong, and Ashton (1998). They obtained HIBS ratings from 55 persons with a TBI and their key relative in 51 of these cases. Internal consistency statistics were high for ratings of the number of items endorsed on the HIBS by both the injured persons and their relatives ( $\alpha = 0.90$  for both versions). The test-retest reliability of the HIBS has been demonstrated with a sample of 27 persons with a TBI who were assessed at 6 months and 18 months following injury (Godfrey et al., 1993). Caregivers' distress ratings were moderately stable over a one-year period ( $r = 0.68$ ).

In the same study (Godfrey et al., 1993) the concurrent validity of the HIBS was examined with regard to a sample of 66 caregivers of persons with a TBI. Caregivers rated the number of problems described in the HIBS that were relevant to their injured relative. Independently, the Social Behaviour Assessment Scale (Platt, Hirsch, & Wehman, 1983) was used to make clinical ratings of severity of problem behaviours displayed by the injured person using. The concurrent validity of the HIBS was supported, with clinician ratings on the Behaviour Problem subscale of the Social Behaviour Assessment Scale correlating 0.65 with caregiver self-report ratings.

Studies have also demonstrated the HIBS to provide a valid measure of symptom self-awareness. For example, Fleming et al. (1998) computed a HIBS self-awareness score by subtracting the number of items endorsed by 55 persons with a TBI from the number endorsed by a significant other. A cluster analysis of scores on a number of measures was used to classify those with TBI as low or high in self-awareness. These measures consisted of the Self-Awareness of Deficits Interview (Fleming, Strong, & Ashton, 1996) and the discrepancy between the person with a TBI and their significant other on the Patient Competency Rating Scale (Prigatano et al., 1986). The self-awareness score on the HIBS differentiated those independently classified as having low or high self-awareness in the cluster analysis, supporting the validity of this index.

Two studies have shown the HIBS to be a sensitive outcome measure. Smith and Godfrey (1995) administered the HIBS at 6 and 18 months post injury. The distress ratings of 14 relatives who took part in a family support intervention were compared with those of relatives from a control group. Relatives who were in the family support condition reported significantly lower distress on the HIBS at 18 months follow-up, than did relatives in the control condition, proving the sensitivity of the HIBS as an outcome measure. Along the same line, Ownsworth, McFarland, & Young (2000) used the HIBS to determine the effects of a 16-week program designed to improve self-awareness and psychosocial functioning following TBI. Twenty-one persons with TBI took part in the group and were rated by a relative on the HIBS at pre- and post- group. Relatives identified significantly fewer TBI related problems on the HIBS post-assessment.

## **Procedure**

Ethical approval for this study was obtained from the National Ethics Committee Waikato Area Office (see Appendix D) and the Massey University Human Ethics Committee (see Appendix E).

Participants were initially contacted by staff at their respective rehabilitation settings. These rehabilitation settings included residential care agencies for people with TBI, day service agencies for people with TBI, Clinical Psychologists' private clients, and support group agencies for caregivers of people with TBI. The settings were selected after consultation with a Clinical Psychologist working in the field of neuropsychology. Staff at the agencies addressed the information packs to each caregiver, to protect their anonymity from the researcher. Each information pack contained a "Participant Information Sheet" (see Appendix F) which described the procedure and rationale of the study, and three assessment questionnaires: a demographic questionnaire, the Social Support Questionnaire, and the Head Injury Behaviour Rating Scale (caregiver version). Caregivers' were invited to complete the questionnaires and mail them back using the prepaid envelope enclosed in the information pack.

## **Data Analysis**

All data was analysed using the computer-based statistical programme SPSS (version 11.0). An alpha level of 0.05 was used to determine statistical significance. Two-tailed tests were mostly used, and in instances when one-tailed tests were employed, this is reported.

Initially, the relationship between dependent and independent variables was examined using correlational analyses. These are described fully in each instance.

Nonparametric procedures were also employed where appropriate. Further, multiple regressions were conducted to test for significant, independent predictors of the dependent variable. All data analyses were then conducted following the procedures outlined in Pallant (2001).

## Results

As shown in Table 2, caregiver reports indicated that the most common services received by their relative with TBI were from an Occupational Therapist (96%), Physiotherapist (92%), and Rehabilitation Assistant (92%), and the

Table 2  
*Treatment Services Received by People with TBI*

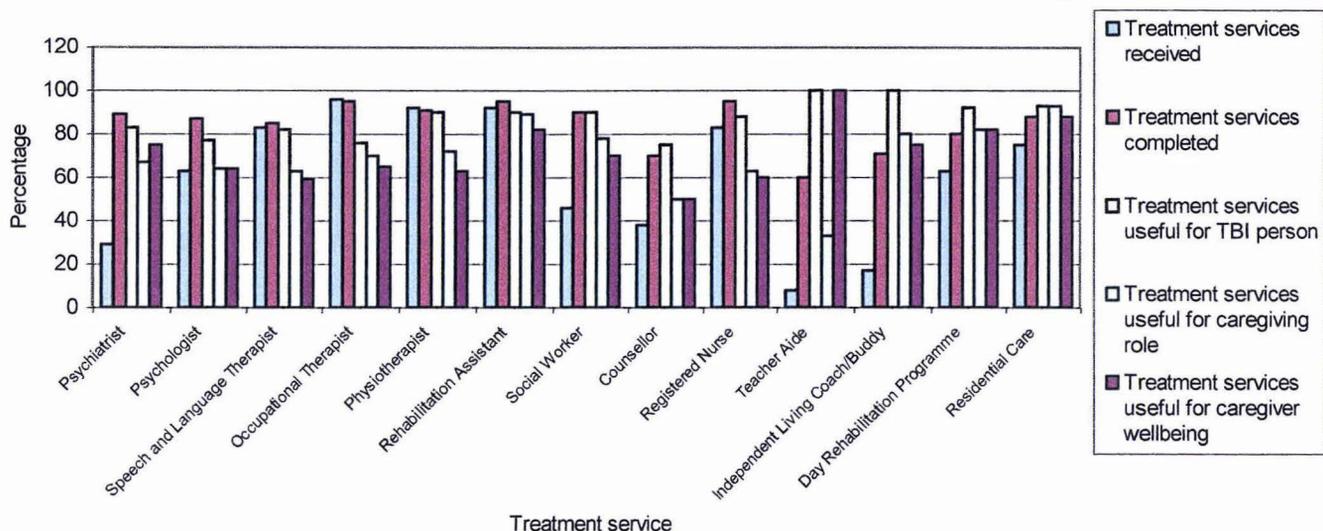
Treatment service	Frequency (%)
Occupational Therapist	23 (96)
Physiotherapist	22 (92)
Rehabilitation Assistant	22 (92)
Speech and Language Therapist	20 (83)
Registered Nurse	20 (83)
Residential Care	18 (75)
Day Rehabilitation Programme	15 (63)
Psychologist	15 (63)
Social Worker	11 (46)
Counsellor	9 (38)
Psychiatrist	7 (29)
Independent Living Coach/Buddy	4 (17)
Teacher Aide	2 ( 8)

least were Independent Living Coach/Buddy (17%) and Teacher Aide (8%). On average, caregivers identified the TBI person as receiving 8 (63%) of a possible 13 treatment services.

Figure 2 shows the completion rates, and helpfulness of services for the person with TBI, as well as for the caregiving role, and caregiver wellbeing. It appears that the Teacher Aide was the treatment service with the highest rate of *non-completion* (40% non-completion), followed by Counsellor (30%) and then Independent Living Coach/Buddy (29%).

The treatment service regarded by caregivers as *most useful* to the person with TBI was also Teacher Aide (100%) and Independent Living Coach/Buddy

(100%). This apparent anomaly is probably best explained by the fact that these services were still being received. The least useful service was Counsellor (75%) followed by Occupational Therapist (76%).

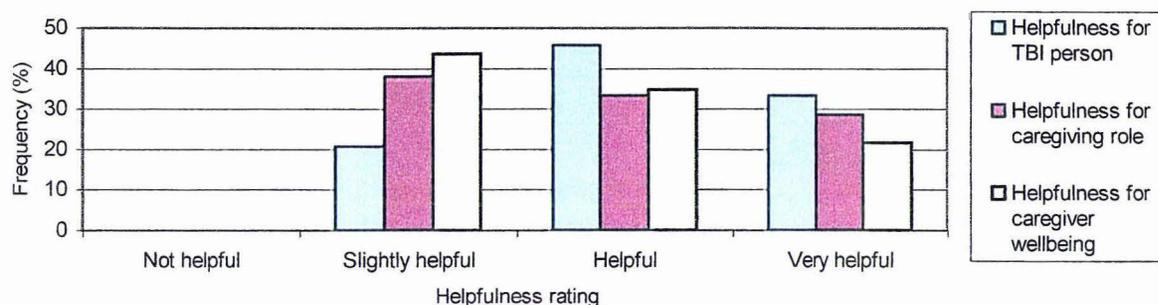


**Figure 2:** Relationship between treatment services received by the person with TBI and caregiver perspective of helpfulness of treatment

In terms of helpfulness for caregiving role, Residential Care (93%) received the most endorsements, followed by Day Rehabilitation Programme (82%). Teacher Aide (33%) and Counsellor (50%) were considered the least helpful for caregiving role.

With regard to caregiver wellbeing, the Teacher Aide (100%) was considered the most helpful, followed by Residential Care (88%). Least helpful were Physiotherapist (63%) followed by Psychologist (64%). Overall, completion rates were high, and treatment services were regarded in high esteem in terms of helpfulness for TBI person, caregiving role, and caregiver wellbeing. Figure 3 shows just this - the helpfulness of treatment services overall for the TBI person, caregiving role, and caregiver wellbeing. For no group were treatment services

overall identified as unhelpful or unsatisfactory. When the categories of slightly helpful, helpful and very helpful were also collapsed and merged into the category of services identified simply as helpful, encouraging results were generated. On average, 85.65% (SD=24.431) of services were identified as helping the TBI person, 72.67% (SD=29.522) as helping caregiver role, and 68.24% (SD=39.977) identified as helping caregiver wellbeing. Treatment services appear to have been the most helpful in assisting caregiver role, rather than caregiver wellbeing, or the helping the TBI person – the person for whom the services were targeting.



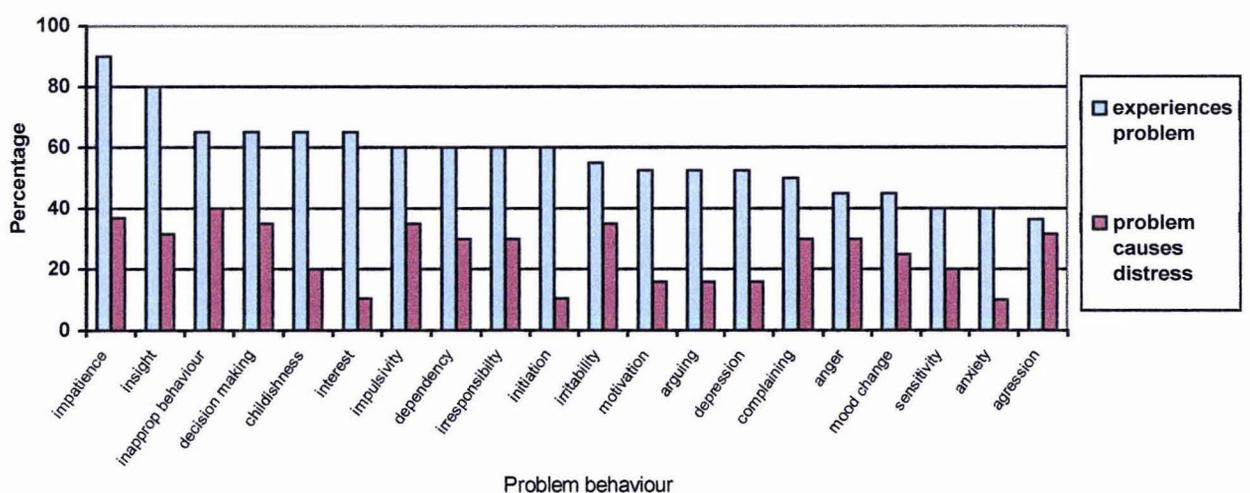
**Figure 3.** Relationship between treatment services received as a group, and perspective of caregiver on the helpfulness of treatment services

Caregiver reports of the level of functioning for the people with TBI are presented in Table 3. The most common problem exhibited by the TBI person was impatience (87%), followed by poor insight (74%). The least common problem exhibited by the TBI person was aggression (36%). For the total sample, the average number of problems exhibited by the TBI person score was 12.18 (SD=3.996) out of a possible 20, and the average level of caregiver distress was 30.91 (SD=14.292). Figure 4 shows the relationship between problems for TBI people and distress experienced by caregivers.

Table 3

*Frequency of Problem Behaviours Exhibited by the TBI person, and Caregivers' Mean Distress Ratings at the Problems Exhibited by the TBI Person*

Problem area	Frequency	Mean distress
Impatience	20 (87%)	2.18
Lack of insight	17 (74%)	1.91
Social inappropriateness	16 (70%)	2.35
Lack of interest	16 (70%)	1.32
Decision making	15 (65%)	1.83
Childishness	15 (65%)	1.57
Lack of initiative	15 (65%)	1.45
Lack of motivation	14 (64%)	1.64
Depression	14 (64%)	1.55
Irresponsibility	14 (61%)	1.64
Dependency	14 (61%)	1.57
Impulsivity	14 (61%)	1.57
Irritability	13 (57%)	1.65
Argumentativeness	12 (55%)	1.36
Frequent complaining	12 (52%)	1.35
Anger	11 (48%)	1.41
Overly sensitive	11 (48%)	1.35
Mood change	11 (48%)	1.22
Anxiety	11 (48%)	1.17
Aggression	8 (36%)	1.50



**Figure 4:** Relationship between problems for TBI people and distress experienced by caregivers

## ***Correlational Analyses***

### Confounding Variables

The first step of the correlational analyses consisted of examining for presence of potential confounding variables. This included an analysis of 11 variables that could possibly be predictive of caregiver distress, but were not amongst the variables identified as possible stressors. These included the age of the caregiver and person with TBI, gender of the caregiver and person with TBI, relationship between TBI person and caregiver, employment status of the caregiver and person with TBI, the time since injury, period of unconsciousness, and number of problems exhibited by the TBI person. The Pearson's Product-Moment Correlation showed the relationship between caregiver distress and number of problems exhibited by the TBI person to be significant ( $r=.801$ ,  $p=.000$ ). The Mann-Whitney U Test showed a significant correlation between caregiver distress and change in caregiver employment status ( $p=.047$ ), at the one tailed level.

### Distress and Type of Social Support

The relationship between type of social support (the social supports received, including Psychologist, Psychiatrist, Speech and Language Therapist, Occupational Therapist, Physiotherapist, Social Worker, Counsellor, Registered Nurse, Teacher Aide, Independent Living Coach/Buddy, Day Rehabilitation, Residential Care) and caregiver response to stressors (as measured by caregiver distress) was examined using the Mann-Whitney U-test. No relationships were significant.

### Distress and Quantity of Social Support

The relationship between objective level of social support (number of social supports received) and caregiver distress was also examined. Using the Pearson Product-Moment Correlation, no relationships were significant. Objective characteristics of social support (type and quantity of social support received) were simply not related to caregiver distress.

### Distress and Perception of Social Support

The relationship between caregiver subjective perception of social support (as measured by caregiver responses to the helpfulness of each treatment service for TBI person, for caregiving role, and for caregiver wellbeing) and caregiver distress resulting from caregiver perception was measured using the Pearson Product-Moment Correlation. A significant positive correlation was found between helpfulness for TBI person and helpfulness for caregiving role ( $r=.787$ ,  $P=.000$ ), and helpfulness for TBI person and helpfulness for caregiver wellbeing ( $r=.645$ ,  $p=.002$ ). This indicates that the more that the services helped the TBI person, the more that they helped caregiving role and caregiver wellbeing. A significant negative correlation was obtained between helpfulness for TBI person and caregiver distress ( $r=-.471$ ,  $p=.027$ ), suggesting the less that treatment services helped the TBI person, the greater the caregiver distress.

The Spearman's Rank order correlation was calculated to establish the relationship between caregiver distress, and caregiver perception of helpfulness of services overall (as measured by Likert Scale rankings of helpfulness of services overall for TBI person, for caregiving role, and caregiver wellbeing, and overall satisfaction level). Significant positive correlations were found between

helpfulness for TBI person and helpfulness for caregiving role ( $r_s=.679$ ,  $p=.001$ ); helpfulness for TBI person and helpfulness for caregiver wellbeing ( $r_s=.655$ ,  $p=.001$ ); helpfulness for TBI person and overall satisfaction ( $r_s=.681$ ,  $p=.000$ ); helpfulness for caregiving role and helpfulness for caregiver wellbeing ( $r_s=.754$ ,  $p=.000$ ), helpfulness for caregiving role and overall satisfaction ( $r_s=.651$ ,  $p=.001$ ); and helpfulness for caregiver wellbeing and overall satisfaction ( $r_s=.662$ ,  $p=.001$ ). Significant negative correlations were obtained between caregiver distress and helpfulness for TBI person ( $r_s=-.417$ ,  $p=.048$ ), and helpfulness for TBI person and overall satisfaction ( $r_s=-.427$ ,  $p=.042$ ). It seems that treatment services helpful for the TBI person are consequently considered helpful for the caregiver. While caregiver *perception* of helpfulness of services for TBI person (subjective quality) is associated with caregiver distress, quantity and type of social support (objective characteristics) are not.

#### Distress and Treatment Noncompletion

The Pearson's Product-Moment Correlation was used to correlate quantity of treatments not completed and the distress experienced by the caregiver. The correlation failed to meet statistical significance ( $r=-.136$ ,  $p=.536$ ). The Pearson Product-Moment Correlation was also employed to examine the relationship between quantity of treatments not completed and caregiver subjective perception of social support (as measured by caregiver responses to the helpfulness of the social support received for TBI person, for caregiving role and for caregiver wellbeing). No correlations met statistical significance.

The relationship between caregiver distress resulting from treatment noncompletion and caregiver distress overall was investigated. The relationship was not significant ( $r=.236$ ,  $p=.435$ ).

The relationship between caregiver treatment noncompletion distress and helpfulness for TBI person, caregiving role, and caregiver wellbeing was also explored. Again, no relationships were significant.

### ***Multiple Regression Analyses***

To further investigate these relationships and to test for significant, independent predictors of caregiver distress, standard multiple regressions were conducted. Preliminary analyses were performed to ensure that there was no violation of the assumptions of sample size, multicollinearity or singularity, outliers and that the assumptions of normality, linearity, and homoscedasticity were met. Caregiver distress level was entered as the dependent variable. Due to the small number of participants in the sample, the results of the regression analyses must be treated with caution and significant results interpreted only as preliminary evidence for patterns in relationships.

The relationship between caregiver distress, number of problems exhibited by TBI person, number of services received, services identified as helpful for TBI person, for caregiver role and for caregiver wellbeing was explored. Caregiver distress and helpfulness for TBI person reached statistical significant ( $B=-.486$ ,  $p=.033$ ), as did caregiver distress and number of problems exhibited by the TBI person ( $B=.744$ ,  $p=.000$ ). This suggests that both helpfulness for TBI person and number of problems exhibited by the TBI person are significant, independent predictors of caregiver distress.

Regressions were also conducted for caregiver distress and the Likert scale rankings made by caregivers on Part II of the Social Support Questionnaire (SSQ) (helpfulness of services overall for TBI person, helpfulness of services overall for caregiving role, helpfulness of services overall for caregiver wellbeing, and overall satisfaction level). Helpfulness for caregiver role was the variable that made the strongest unique contribution to explaining caregiver distress (the dependent variable) when the variance explained by the other variables (percentage of services received, percentage of helpfulness of services for caregiver role and percentage helpfulness of services for caregiver wellbeing) was controlled for. However, it failed to reach statistical significance ( $B = -.401$ ,  $p = .324$ ). This negative correlation indicates that the less that treatment services helped caregiver role, the greater the distress, but not to a statistically significant degree.

Further regressed was caregiver distress due to treatment noncompletion and the Likert scale rankings made by caregivers on Part II of the SSQ (helpfulness of services overall for TBI person, helpfulness of services overall for caregiving role, helpfulness of services overall for caregiver wellbeing, and overall satisfaction level). No variables met statistical significance, however overall satisfaction made the strongest unique contribution to explaining caregiver distress (the dependent variable) when the variance explained by the other variables was controlled for ( $B = .825$ ,  $p = .702$ ).

When caregiver distress due to treatment noncompletion was regressed number of services received, number of services not completed, helpfulness for TBI person, caregiving role, and caregiver wellbeing, with no relationships met statistical significant. Helpfulness for caregiving role made the strongest unique

contribution to explaining caregiver distress (the dependent variable) when the variance explained by the other variables was controlled for ( $B=.922$ ,  $p=.174$ ).

## Discussion

The purpose of the present study was to investigate in detail the impact of social support on caregiver burden and also the impact of the caregiver's *perception* of that social support on their distress levels. In this regard, social support as an intervention was examined with reference to the buffering hypothesis and the Stress Appraisal Coping (SAC) model. The buffering hypothesis states that social support buffers or attenuates the effects of stress and has been supported by numerous studies (Esterling et al., 1994; Thompson et al., 1993; Zarit et al., 1980). The difficulty with this model is that appraisal of an event must precede any stress reaction. Reformulated, it is the caregiver's subjective *appraisal* of social support, rather than social support alone, that has the ability to decrease or increase caregiver burden levels (Harris et al., 2001), as stated by the Lazarus' (1966) SAC model (SAC). The SAC model proposes that individuals experience emotional distress when they appraise their environmental demands as exceeding the personal and social coping resources available to them. This leads to depression, low self-esteem and anxiety. With caregivers of people with TBI, these responses are said to be mediated by (1) carer's appraisal of the changes (threat perception); (2) the effectiveness of coping mechanisms that carers utilise; and (3) the amount of, and satisfaction with social and professional support received (Harris et al., 2001).

The present study suggests that interventions designed to improve support for carers will be productive only if they are perceived as useful and relevant by the caregivers. This was most noticeable when discerning the usefulness of various support roles, whereby 100% of respondents found the direct or 'hands on' interventions such Teacher Aide and Independent Living Coach/Buddy as

most useful, while 75% viewed the indirect or 'self directed' intervention of Counseling as being least useful. In this regard, it is proposed that for self-directed intervention, more emphasis should be placed on the carers' subjective perception of the support being provided, and its usefulness within TBI rehabilitation. This emphasis could better prepare the carer for the long-term, allowing them to bring about rehabilitative change on a day-to-day basis and avoid an over reliance on resource intensive intervention which more often than not, has a finite lifespan.

Cognitive restructuring is one example of a tool a clinician can utilise to facilitate long-term satisfaction as well as increase the perception of the usefulness of the indirect interventions. Very little research has been undertaken in regard to the SAC model with reference to the TBI population. This study was therefore exploratory in nature, the aim being to provide preliminary research in this area.

### ***Caregiver Distress and Subjective Social Support***

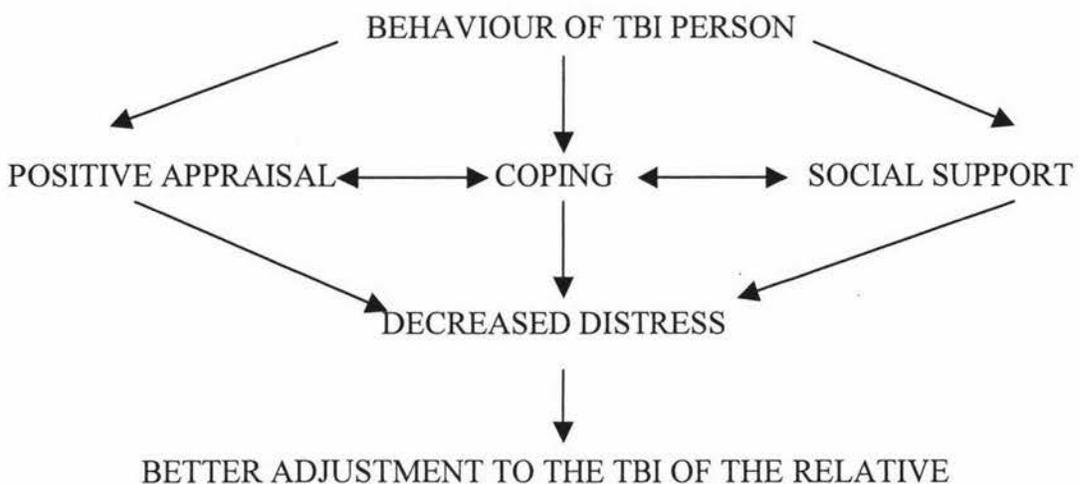
The first hypothesis of this study was that the relationship between social support and caregiver burden would be mediated by the subjective appraisal of the effectiveness of that social support and would be capable of buffering or attenuating against caregiver burden distress levels. Specifically, it was posited that caregivers satisfied with the support provided would have decreased burden levels. In contrast, caregivers dissatisfied with the support provided would have increased burden levels.

There is a plethora of research suggesting that simply providing social support helps alleviate caregiver burden (e.g., Douglas & Spellacy, 2000;

Kosciulek et al, 1993; Lezak, 1998; Moules & Chandler, 1999). The findings of this research suggest that this hypothesis maybe more complex than previously thought. In this respect it was found that it is caregiver *perception* of social support that is associated with caregiver burden, rather than social support alone. This supports the few studies that acknowledge the importance of appraisal in mediating response to stress. For example, in their study, Godfrey et al. (1996) conceptualized the emotional adjustment of the person with TBI, to their injury within the SAC model and found strong preliminary evidence. Research by Knight et al. (1997) regarding the burden experienced by spouses of people with Multiple Sclerosis (MS) found that individual differences in burden could be accounted for by the carers' appraisal of the symptoms, perceived social support, and satisfaction with coping. Within the TBI caregiving population, Harris et al. (2001) found that carer appraisal of adverse family effects mediated the relationship between stressor and depression, and carer perception of support effectiveness moderated the effect of adverse family effects on depression. However, Harris et al. (2001) still concluded that decreasing caregiver burden levels lies simply in providing support.

Findings of the present study indicate that caregiver distress was related to caregiver overall satisfaction with services, the latter in turn related to helpfulness for TBI person, and caregiving role, and caregiver wellbeing. Further, caregiver distress was related to the effectiveness of the social support for the TBI person. Both correlations were negative, with greater distress associated with higher levels of dissatisfaction with overall services, and a poorer perception of the helpfulness of treatment services for the TBI person.

With respect to the SAC model (Lazarus, 1966), correlations between these variables can be viewed as follows. The stressors in this case are the behaviours of the person with the TBI. Stress responses are caregiver distress. The mediating variable influencing the severity of caregiver distress and modifying the impact of the stressor, is perception of social support, independent adverse behaviours exhibited by the TBI person. As a whole then, it can be said that the caregivers' positive perceptions of the effectiveness of the social support provided for the person with TBI, buffered or attenuated against stress. These relationships are illustrated in the diagram below which is a modified version of Lazarus' original diagram (Godfrey et al., 1996) showing that the more that social support is perceived as useful and relevant by caregivers (i.e., the more that the stressor is moderated), the less the caregiver burden (which is mediated by perception).



Interestingly, helpfulness for TBI person was positively and significantly correlated with helpfulness for caregiving role and caregiver wellbeing. This suggests that the more effective that treatment services were in helping the TBI

person, the more effective that they were in helping caregiving role and caregiver wellbeing. This may be because helping the TBI person develop and/or strengthen skills and/or abilities and become more independent indirectly eases the caregiving role and helps with wellbeing by lessening burden. However, treatment services were not sufficiently effective in helping caregiving role and caregiver wellbeing that they were significantly correlated with caregiver distress.

These results perhaps indicate that for helpfulness to the caregiving role and caregiver wellbeing, and to ease caregiver distress, caregivers themselves need to be specific targets of treatments, rather than benefiting indirectly to interventions aimed at the TBI person. That caregivers need direct support, rather than support as a by-product of the services for the TBI person, is a point highlighted and emphasized by Florian et al. (1989). If helping the person with TBI assists the caregiver in achieving better health, then it is highly likely that the inverse is also true, that helping the caregiver likewise assists the TBI person in achieving greater functioning and having greater quality of life.

### ***Treatment Noncompletion and Caregiver Distress***

The second hypothesis stated that treatment non-completion would be positively related to increased caregiver burden levels. The rationale for the hypothesis was that noncompletion of treatment by TBI people was likely to add to caregiver burden, as it would constitute the loss of a social support intervention. Interestingly, the results of this study fail to support this hypothesis. Noncompletion of Treatment was not related to caregiver distress. As this study is exploratory, the nature of treatment noncompletion was not sought. The answer to this lack of relationship may lie in the reason for treatment noncompletion. It

could have been that treatments not completed by the TBI person were simply ineffective, and this being the case, caregivers were indifferent. Reasons for treatment noncompletion by people with TBI and the reactions of caregivers in this regard is an area in need of further research.

### ***Caregiver Distress and Objective characteristics of Social Support***

The third hypothesis stated that the number of social supports would not be related to caregiver burden. This is because it was conceptualised that the key indicator of social support is not number, but perception of effectiveness of that support. In this regard, the hypothesis was supported. Type and quantity of social support was not significantly related to caregiver distress, while *perception* of social support was, both in terms of caregiver overall satisfaction and caregiver perception of helpfulness of treatments for the TBI person. If support interventions are not perceived as valuable by carers, no matter how many are provided, they will simply not alleviate distress. They may in fact have an opposite effect and in themselves be regarded as frustrating and burdensome.

The current findings confirm the view of Stuckey et al. (1996) on the importance of examining not only the objective characteristics of caregiver burden, but also the subjective perspective of the carer. This point is also made by Harris et al. (2001), who emphasised that cognitive processes mediate and moderate the effects of stress.

### ***Caregiver Distress and Demographic Variables***

This study included an analysis of 11 variables that could possibly be predictive of caregiver distress, but were not expected moderate the relationship

between social support and caregiver burden. These included the age of the caregiver and person with TBI, gender of the caregiver and person with TBI, relationship between TBI person and caregiver, employment status of the caregiver and person with TBI, the time since injury, period of unconsciousness, and number of problems exhibited by the TBI person. Identified as significant relationships were caregiver distress and number of problems exhibited by the TBI person, and change in caregiver employment status.

One of the ideas put forward in this study was that there would be a progressively negative relationship between perceptions of social support and caregiver distress levels, and that this relationship would be independent of the static predictors caregiver burden (the TBI person's physical impairment, number of behavioural problems, and social isolation) identified by Marsh et al. (1998). While number of problems was significantly correlated with caregiver distress, independent of this, helpfulness for the person with TBI was correlated with caregiver distress. In hindsight, it is not surprising that there was a correlation between number of problems exhibited by the TBI person and caregiver distress level. This is because the HIBS requires the caregiver to associate whether a problem is exhibited by their TBI relative and if it is, the consequent distress it causes. Regardless, multiple regressions identified helpfulness for TBI person as a significant predictor of caregiver distress independent of number of problems.

No significant relationship was found between time since TBI and caregiver distress. This is surprising in light of the research by Stebbins and Leung (1998), who found that family needs in Australia increased to include the need for caregiver support, among other things. They suggested this finding was due to family carers being faced with an increasing number of problems with continued

time since injury. Along the same line, it was interesting that there was no correlation between severity of injury (as measured by length of coma) and caregiver distress. Research indicates that the more severe the injury, the greater the subjective burden for the relative. Some add that this relationship only holds up to a PTA of approximately two weeks (Brooks et al., 1986; 1987; Brooks & McKinlay, 1983; McKinlay & Brooks, 1984; Peters et al., 1990). In this case whether one day or twelve years, length of coma had no significant effect on caregiver distress. Possible explanations for this finding could be that carer perceptions of the injury needed to be explored further and/or that a greater sample size needs to be employed to determine statistical significance.

A further unusual finding was the lack of significant correlation between the variables "relationship between caregiver and TBI person" and "caregiver distress". This may be due to the sample of this study containing only limited number of cases for each type of relationship. The majority of research suggests that wives have more difficulties in dealing with the consequences of TBI (Brooks, 1984; Kosloff, 1987; Lezak, 1988; Silberg, 1983, cited by Florian et al., 1989; Thomsen, 1984; Thomsen, 1974; Serio, et al. 1997; Kreutzer, & Witol, 1997). Explanations for this include that wives: experience a complete shift in role (Brooks, 1984; Kozloff, 1987; Lezak, 1988; Silberg, 1983, cited by Florian et al., 1989; Thomsen, 1984; Thomsen, 1974; Serio et al., 1997; Kreutzer, & Witol, 1997); are suddenly forced to bear the brunt of the responsibility for the children in the relationship (Brooks, 1991; Jacobs, 1983-1984; Maus-Clum & Ryan, 1981; Panting & Merry, 1972; Rosenbaum & Najenson, 1976) and finances (Brooks, 1991; Jacobs, 1988; Serio et al., 1997); become the decision maker for the family in the absence of instrumental and emotional support from a partner (Florian et

al., 1989; Rosenbaum & Najenson, 1976); may deal with conflict with in-laws who disapprove of their stance (Rosenbaum & Najenson, 1976); may be placed in a role of dual loyalties between the children and the father (Lezak, 1978; Rosenbaum & Najenson, 1976); experience social isolation due to feeling embarrassed about the partners inappropriate behaviour (Brooks, 1991; Kozloff 1987; Oddy & Humphrey, 1980; Rosenbaum & Najenson); and experience loss of intimacy and of a sexual relationship (Brooks, 1991; Lezak, 1978; 1995; McKinlay et al., 1981; Price, 1985; Rosenbaum & Najenson, 1976; Wood, 1984, cited by Florian et al., 1989).

It is somewhat unexpected that caregiver distress was correlated with caregiver change in employment status. This is possibly because 8% of caregivers changed from unemployed before TBI to employed after TBI. Perhaps being a caregiver meant having to get a job, to financially cater for the injured relative, as found by (Brooks, 1991; Jacobs, 1988; Serio et al., 1997).

Overall however, the results of this study did confirm a globally accepted phenomenon. Essentially, caregiver's never completely adjust to TBI, and that burden persists many years after injury (Brooks et al., 1986; Florian et al., 1989; Knight et al., 1998; McKinlay et al., 1981; Oddy et al., 1978; Rappaport et al., 1989; Thomsen, 1984).

### ***Methodological Issues and Implications***

One of the major methodological limitations of this study was the small sample size of this study. According to Stevens (1996), when group size is small (e.g., n=20), it is important to be aware of the possibility that nonsignificant results may be due to insufficient power. It may then be necessary to adjust the

alpha level to compensate, such as in this study when alpha was set at .05 rather than .01. Small sample size may also become an issue when conducting multiple regressions, as with small samples a result may not generalise in that it cannot be repeated with other samples. This means that the result has little scientific value (Pallant, 2001). For this reason, it is necessary to exercise caution when interpreting results of the multiple regressions in the current study. They should be viewed as preliminary evidence of relationships that are in need of further exploration.

The choice of measures is also a limitation of this study. As the intention was to send questionnaires out to participants, the author was very much aware that the questionnaires had to be simple and instructions comprehensible in order to avoid participants making errors in completing the questionnaires. At the same time, questionnaires could not be overly time consuming, or response rate would be compromised. With these considerations in mind, what resulted were questionnaires fairly broad in assessment of burden. In terms of psychiatric morbidity, this meant that only caregiver distress was evaluated, rather than the usual caregiver depression, which is believed to be the most common response to TBI for both sufferers and carers (Brooks et al., 1987; Kreutzer et al., 1994i; Lezak, 1978, 1986; Linn, Allen, & Willer, 1994; Livingstone, 1987; Livingstone et al., 1985i; Maus-Clum & Ryan, 1981; Oddy et al., 1978; Olver, Ponsford, & Curran, 1996; Rosenbaum & Najenson, 1976; Tyerman & Humphrey, 1984; Wilkinson, Fisher, & Bromfield, 1989).

A further limitation of this study was the absence of an opportunity for the carer to express any satisfaction i.e., positive aspects of their "job" as the primary caregiver of a person with TBI. This view is also expressed by Harris et al.

(2001). Too few studies look at the rewarding side of being a carer. Moreover, the study investigated only one side of the story – the perspective of the caregiver. It could be that the perspective of the person with TBI regarding treatment services influences caregiver perception, lessening or increasing distress level.

As with most studies involving surveys, the response rates to the questionnaires were very low. This study is therefore vulnerable to the criticism that low rates of return may have biased the interpretation of the findings, and may also reduced the validity of the results.

Despite the limitations, these data do provide encouraging preliminary findings, that supports the model advanced by Lazarus in 1966 when applied to the TBI population.

### ***Conclusion***

While there have been a number of static predictors identified as being predictive of caregiver burden, namely, the type of physical impairment, the number of behavioural problems, and social isolation (Marsh et al., 1998) the current exploratory study identified a more robust and dynamic predictor of caregiver burden. Progressively negative relationships were found between helpfulness of social support as an intervention for the TBI person, and caregiver distress levels, and caregiver overall satisfaction with support services and caregiver distress. These relationships were independent of the static predictor of number of behavioral problems identified by Marsh et al. (1998). Unlike the static predictors of burden, perception is a useful theoretical construct from which to formulate caregiver distress to TBI, as it is an *active* process (Dagnan & Sandhu, 1999) and consequently, is amenable to modification. The task now is to

identify what interventions may be able to modify caregiver perception, and buffer against caregiver distress. Cognitive therapy, which is a psychological intervention with a large evidence base, may be the avenue through which to achieve change in perception (Lambert & Bergin, 1994). Specifically, researchers have found cognitive reframing and cognitive restructuring as useful in achieving reductions in caregiver stress (Kosciulek et al., 1993; Minnes et al., 2000). The results of this study suggest that targeting caregiver perceptions of the usefulness of indirect interventions would be potentially most pivotal to decreasing caregiver burden, and assisting in the rehabilitation of the person with TBI.

While there has been a mass of research conducted on how caregivers perceive their injured relative's problems, (for example, Alfano et al., 1994; Florian, et al., 1989; Oddy et al., 1978; Weddell et al., 1980), previously, very little research has been attempted in regard to caregiver appraisal of social support and adjustment to TBI. Caregiving has a number of negative (and positive) consequences, and there are considerable individual differences in the success with which this stress is managed. Social support can help caregiver distress. However, it will only do so if perceived as useful and relevant by the carers. Moreover, assisting caregivers will ultimately benefit TBI people, who will reap the rewards of having a stronger and healthier caregiver.

Future research should investigate whether cognitive therapy intervention can be used to intervene the process of caregiver perception of social support provided for the TBI person, and caregiver distress.

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## Appendix A



## Appendix B

## **SOCIAL SUPPORT QUESTIONNAIRE**

This questionnaire is to be completed by the primary caregiver of a person with a brain injury to so that we can ascertain which specialised treatment services provided for people with brain injury are helpful to them, and helpful to their caregivers. A primary caregiver is someone who knew the person with the brain injury prior to their brain injury, who is close to them and who has had regular contact with them since their brain injury.

### **INSTRUCTIONS:**

On the next page is a list of specialised treatment services often provided for people with brain injury. Please indicate which of the specialised treatment services listed has been or is currently provided for the person that you know who has a brain injury by ticking either in the YES column or NO column. Then answer the questions that follow by ticking either the YES, NO or N/A box in regard to those specialised treatment services that have been or are currently being provided for the person that you care for.

On the last page are seven questions. Consider the specialised treatment services received overall and circle the option that best describes how you feel.



Considering the treatment services that you've received overall across all professions:

1. Were/are the specialised treatment services *helpful for the person* with the brain injury that you are close to?

**Not helpful**                      **Slightly helpful**                      **Helpful**                      **Very helpful** (please circle)

2. Were/are the specialised treatment services provided for the person you are close to *helpful to you* in terms of assisting your role as caregiver (e.g., mood of person better so they are easier to get along with)?

**Not helpful**                      **Slightly helpful**                      **Helpful**                      **Very helpful** (circle one)

3. Were/are the specialised treatment service(s) provided for the person you are close to *helpful to you* in terms of your own well-being (e.g., made you happier, more energetic, sleep better)?

**Not helpful**                      **Slightly helpful**                      **Helpful**                      **Very helpful** (circle one)

4. What is your overall level of *satisfaction*?

**Not satisfied**                      **Slightly satisfied**                      **Satisfied**                      **Very satisfied** (circle one)

5. If the person that you are close to did not complete the specialised treatment service(s), overall, how much did this *distress* you?

**Very distressed**                      **Distressed**                      **Slightly distressed**                      **Not distressed** (circle one)

6. Do you feel there were services you wanted but didn't receive for the person with the brain injury that you are close to?

**YES**                      **NO**                      (circle one)

If YES, what services would you liked the person that you care for to have received?.....

.....  
.....  
.....

7. Did you receive any specialised treatment services *for yourself* (e.g., counselling)?

**YES**                      **NO**                      (circle one)

If YES, how *helpful* were the specialised treatment services *provided for you* in terms of your own well-being (e.g., made you happier, more energetic, sleep better)?

**Not helpful**                      **Slightly helpful**                      **Helpful**                      **Very helpful** (circle one)

## Appendix C

# HEAD INJURY BEHAVIOUR SCALE

Relative/Friend Version

To be completed by relative or friend of the sufferer

Hamish P D Godfrey PhD  
Clinical Psychology Research and Training Centre  
University of Otago, New Zealand

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**INSTRUCTIONS:** On the next page is a list of problem behaviours the sufferer may be experiencing. Please indicate which of the behaviours listed is a problem for the sufferer by circling YES or NO as appropriate. For each problem behaviour circled YES, please indicate how much distress the behaviour causes YOU by circling a number on the scale (1-4). Remember we are asking you to report about the sufferers behaviour. Use the rating scale given at the top of the next page.

## HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for sufferer but causes me NO distress.
2. The behaviour is a problem for sufferer and causes me MILD distress.
3. The behaviour is a problem for sufferer and causes me MODERATE distress.
4. The behaviour is a problem for sufferer and causes me SEVERE distress.

BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?			
1. Anger; difficulty controlling temper.	Y : N	1	2	3	4
2. Impatience, upset when needs not easily met.	Y : N	1	2	3	4
3. Frequent complaining.	Y : N	1	2	3	4
4. Aggression; violent behaviour.	Y : N	1	2	3	4
5. Impulsivity; does things without thinking.	Y : N	1	2	3	4
6. Argumentative; often disputes topics.	Y : N	1	2	3	4
7. Lacks control over behaviour behaviour is inappropriate for social situations.	Y : N	1	2	3	4
8. Overly dependent; relies on others unnecessarily; does not do things for him/herself.	Y : N	1	2	3	4
9. Poor decision making; does not think of consequences.	Y : N	1	2	3	4
10. Childish; at times behaviour is immature.	Y : N	1	2	3	4

## HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for sufferer but causes me NO distress.
2. The behaviour is a problem for sufferer and causes me MILD distress.
3. The behaviour is a problem for sufferer and causes me MODERATE distress.
4. The behaviour is a problem for sufferer and causes me SEVERE distress.

BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?			
11. Poor insight; refuses to admit difficulties.	Y : N	1	2	3	4
12. Difficulty in becoming interested in things.	Y : N	1	2	3	4
13. Lack of initiative; does not think for him/herself.	Y : N	1	2	3	4
14. Irritable; snappy; grumpy.	Y : N	1	2	3	4
15. Sudden/rapid mood change.	Y : N	1	2	3	4
16. Anxious; tense; uptight.	Y : N	1	2	3	4
17. Depressed; low mood.	Y : N	1	2	3	4
18. Irresponsible; can't always be trusted.	Y : N	1	2	3	4
19. Overly sensitive; easily upset.	Y : N	1	2	3	4
20. Lacks motivation; lack of interest in doing things.	Y : N	1	2	3	4

## Appendix D

# Waikato Ethics Committee

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HAMILTON

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29 July 2002

Waikato Ethics Committee Ref No. WAI/02/06/041

Please include this reference number and study title in all correspondence

Julie Fraser  
15 Gibson Road  
Dinsdale  
HAMILTON

Dear Julie

## **Views of family members on the effects of Traumatic Brain Injury**

**WAI/ 02/06/041**

Thank you for your letter of 12 July 2002 and for addressing the concerns of the committee and for forwarding revised copies of the Information Sheet and the Consent Form. You have addressed the concerns of the Waikato Ethics Committee and ethical approval is now given.

### **Approved documents**

Information Sheet / Consent Form: version II 03/07/02.

The Committee certifies that it is satisfied that this trial is not being conducted principally for the benefit any manufacturer or distributor of medicine or any item in respect of which the trial is carried out. This certification is for the purposes of the Injury Prevention, Rehabilitation and Compensation Act 2001.

Ethical approval is conditional upon the Committee receiving annual progress reports on the study, a final report at the completion of the study, and a copy of any publication. Please notify us of any adverse reactions or if the study is abandoned or you wish to change the protocol in any way.

Best wishes for the success of your study.

Yours sincerely



Peter D Allan  
Chairperson

## Appendix E



25 September 2002

Julie Fraser  
15 Gibson Road  
HAMILTON

Dear Julie

**Re: MUHEC: WGTN Protocol - 02/118**  
**Views of Family Members on the Effects of Traumatic Brain Injury**

Thank you for your letter of 5 September 2002 and the amended documents incorporating the changes recommended by the Massey University Wellington Human Ethics Committee.

The amendments you have made now meet the requirements of the Massey University Human Ethics Committee and the ethics of your protocol are approved.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Human Ethics Committee for further consideration and approval.

A reminder to include the following statement on all public documents. "This project has been reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 02/118. If you have any concerns about the conduct of this research, please contact Dr Pushpa Wood, Chair, Massey University Wellington Human Ethics Committee, telephone 801 2794 ext 6723, email P.Wood@massey.ac.nz."

Yours sincerely


Dr Pushpa Wood (Chair)  
Massey University Human Ethics Committee: Wellington

Cc: Professor Janet Leathem

Te Kunenga ki Pūrehuroa

Inception to Infinity: Massey University's commitment to learning as a life-long journey



## Appendix F



**Coping with the Aftermath of Traumatic Brain Injury:  
The views of Relatives and Close Friends**

**INFORMATION SHEET**

We are seeking participants in the Auckland, Wellington, Waikato, Manawatu and Taranaki regions for a study that we are conducting about how people cope with the aftermath of traumatic brain injury. Earlier studies have asked the people with brain injury, but this time, we are interested in the views of the people *closely associated* to a person with traumatic brain injury, e.g., family member or close friend. Talking to people about what factors were helpful (and perhaps not so helpful), will provide evidence to assist in ensuring that the most helpful services are available after the injury, both for the person with the injury as well as their wider family.

Your participation will involve completion of some questionnaires asking about your experience of the trauma of brain injury as it has affected you, even though you would not have sustained the injury yourself. Completed questionnaires can be returned in the prepaid self-addressed envelope provided.

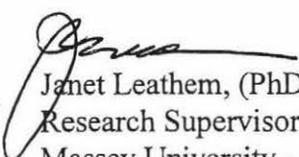
You can be assured that if you decide to participate, your answers will remain completely confidential. You don't have to answer all question or questions. We realise that you may not be in a position to answer some of them. Questions about the study can be asked at any time, and you can choose to withdraw from the study at any time. Whether or not you decide to participate has no bearing at all on any current or future treatment or rehabilitation. The information you provide will not be passed on to ACC and will not affect ACC claims.

Later the information will be summarized and analyzed to form the basis of a Master's thesis research report. As results will be grouped and/or made anonymous, your responses will not be identifiable. All data will be destroyed at completion of the study.

If you wish to discuss any aspect of the study, or to volunteer to participate, please contact the principal researcher Julie Fraser below. If you would like to receive a summary of the findings of the study when it is concluded please leave a message on the phone number below.

Thank you for considering our request for participation.

Julie Fraser   
Masterate Student  
Palmerston North: (06) 350 5799 extn 9773  
Wellington: (04) 801 2794 extn 9773  
Auckland: (09) 443 8157 extn 9773

  
Janet Leathem, (PhD)  
Research Supervisor  
Massey University - Wellington

This project has been reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 02/118. If you have any concerns about the conduct of this research, please contact Dr Pushpa Wood, Chair, Massey University Regional Human Ethics Committee: Wellington, telephone 04 801 2794 ext 6723, email [P.Wood@massey.ac.nz](mailto:P.Wood@massey.ac.nz). The National Human Ethics committees have also approved this research.