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PERCEIVED STRESS IN PARENTS AND PARTNERS  
OF PEOPLE WITH HEAD INJURY

A thesis presented in partial fulfillment of  
the requirements for the degree of  
Master of Arts in Psychology  
at Massey University

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1992

**ABSTRACT**

The stress experienced by Parents and Partners of people with head injury has been examined by several authors, especially in relation to a number of clinical issues. There is general agreement between researchers and clinicians alike that relatives of people with head injuries experience heightened stress as a result of the injury and its consequences. The present study sought to examine the stress experienced by Parents and Partners of people with head injury by focussing on minor events, along with several related variables. A single structured interview, including both verbally administered and written response questionnaires was completed with 18 Parents and 13 Partners. Measures included the Daily Hassles and Uplifts Scale, the Arizona Social Support Interview Schedule, questions regarding Role Change, Health Problems and the Information received at the time of hospitalisation. The combined Parents and Partners group indicated that they experienced moderate levels of Stress and Role Change. A relatively small proportion of participants reported experiencing Health Problems. Partners indicated a slightly higher degree of Stress and a greater degree of Role Change than Parents, and a larger proportion of Partners indicated the presence of Health Problems. Qualitative differences between the two groups were found in terms of sources of Stress. There was little quantitative or qualitative difference in Social Support. Positive correlations were found between Stress and Role Change and Stress and Health Problems. Participants indicated that, in general, the information received at the time of hospitalisation was not satisfactory. Their level of understanding and the perception of the adequacy of this information increased over time. The results obtained supported a number of the research hypotheses in showing that some differences do exist between the two groups, although generally these differences were not large. A number of suggestions for future research and service provision arose from the results obtained.

## ACKNOWLEDGEMENTS

There are a number of people I would like to thank for their assistance and support in the preparation of this thesis. First of all, my supervisors, Cheryl Woolley and Janet Leathem, for their support, guidance and understanding, throughout what has been a very long process.

My thanks must also go to the participants in the study, and their families, who shared with me some of their experiences, and allowed me a small measure of understanding.

John Spicer was very helpful, and gave me valuable advice regarding analysis issues. The Office Staff of the Psychology Department and the Psychology Clinic Secretary were always helpful.

Special thanks to my family for their support, Mum especially. My flatmates, Ange and Steve, have been my friends through the whole process, and I have valued their support and encouragement also.

Thanks also to my employers and my co-workers for their patience and help in allowing me time from work.

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## CHAPTER 1 - INTRODUCTION

### Purpose

The purpose of the present research is to examine and describe aspects of perceived stress experienced by a group of parents and partners of people with head injury. The aim is to determine whether qualitative and quantitative differences in perceived stress exist between these two groups. Role Changes, Social Support, Health Problems and Coping will also be examined.

The wider purpose of the present study is to contribute to the body of knowledge that is accumulating about the effects of head injury on relatives of people with head injuries. In addition, it aims to improve the quality of therapeutic interventions that are used to help this group of people by providing information about some of their needs and strengths.

The direction of the present study was prompted, in part, by the areas identified by Cannon (1989) as needing more research. The most relevant of these was the vulnerability of different types of family relationships to stress following head injury. The equivocality and scarcity of the literature concerned with this area, as outlined in Chapter 2, also provided motivation for the direction of the present research.

### Scope

The present study is a cross-sectional study, with a deep and narrow focus on one particular area in head injury research - the relative vulnerability of parental and partner relationships in response to severe head injury. It also examines some of the factors that may affect this vulnerability.

Because the present study examines a number of variables with relation to the area of focus, it is largely exploratory. Thus there are three general aims inherent in this research. The first is to examine the stress experienced by parents and partners of people with head injury, and variables that may be related to this. The second is to determine whether there are any differences between these two groups in terms of these variables. The third and final aim is to generate hypotheses for future research in this area from the results obtained.

### Terminology

The term 'caregiver' is frequently used in literature concerned with people with disabilities, including head injuries. It is used to describe a number of functions and roles played by people who are often family members. The term 'caregiver' has been avoided in the present study because people with head injuries in general, and specifically the people involved in the present study, do not consider themselves to be in need of care per se.

The people interviewed are interchangeably referred to as participants or Parents and Partners groups, either in combination or separately. The term 'client', 'person with head injury' or 'head injured person' is also used to refer to the participants' sons/daughters/partners in preference over any other term.

### Organisation

The thesis consists of four major sections - Introduction, Method, Results and Discussion. The Introduction consists of the first four chapters which cover the major areas relevant to this research. Chapter One deals with the purpose and organisation of the present study. Chapter Two reviews the literature concerned with head injury and its effects on the family. Chapter Three deals with theories of

stress and reviews the literature relevant to this study. And Chapter Four is concerned with the research hypotheses and gives a synthesis of the two previous chapters.

The method section is contained in Chapter Five, and the results of the present study are contained in Chapter Six. The discussion of the results and their implications occupies Chapter Seven.

## CHAPTER TWO - LITERATURE REVIEW - HEAD INJURY AND THE FAMILY

### Introduction

This chapter is organised into several sections. The first provides background information by outlining the extent of the problem and what families have to deal with when one of their members sustains a head injury. The following section outlines the types of deficits which may arise from head injury. This is followed by two sections concerned with the families of people with head injury, the main features of family burden, and an overview of the types of relationships that are most vulnerable following head injury.

### Context

"The topics and methods chosen for scientific investigation are partially a reflection of the scientists' lives and times" (Conrad & Maul, 1981, p 327). That this topic area was chosen for research in the present study to an extent reflects the fact that the incidence and public awareness of head injury in New Zealand is increasing. Advances in medical technology mean that more people with head injuries are surviving and are surviving for longer. The issues raised in this section will provide some idea of what many families face when one of their members is head injured. It will also illustrate the necessity for research in this area.

Each week in New Zealand, almost 200 people are admitted to hospital with head injuries and another 400 are treated but not admitted (Gronwall, Wrightson & Waddell, 1990). For the year ended March 1989, the Accident Compensation Corporation (ACC) (NZ) registered 5093 claims for "injury to the head", excluding injury to the face. Of these, 4105 claims were made by men, and 988 by women (Accident Compensation Corporation, 1989, cited in Cannon, 1989). In the 1990 figures released by the ACC, a total of 7098 claims for injuries of the same

nature were registered. Of these, 5426 were lodged by males, and 1672 by females (Accident Compensation Corporation, 1990, cited in Cannon, 1989). These two sets of figures illustrate two facts. Most obvious is the drastic increase in the total number of claims of this nature. Less apparent, but just as important is the increasing proportion of females registering such claims.

Claims made for multiple injury also often include head injuries (Accident Compensation Corporation, 1989, cited in Cannon, 1989), so many incidences of head injury may actually not be accounted for in the head injury statistics.

The changes that may result from head injury can be both severe and long-lasting. Crawford (1983) remarks that less than one in ten people with severe head injury "is ever likely to be the same again" (p 973).

A number of demographic trends can be identified among people with head injury and some projections can be made from these. Men are three to six times more likely than women to receive head injuries. Head injuries are most common in the 15 to 24 year old age group. A majority of people with head injuries are from lower socioeconomic groups. Fifty percent of head injuries result from motor vehicle accidents, and alcohol is involved in a similar proportion of such injuries (Rimel & Jane, 1983; Bond, 1984). Thus, it seems that cultural and social characteristics increase the risk of injury in young men. Personality characteristics such as youthful impulsivity, aggression, and the liability to take risks set the scene for brain injury in young men (Bond, 1984).

Overall the picture is very grim. The reality is that many people have their lives shattered by head injury, not only the injured themselves, but also their families, friends, and colleagues. These people have to come to terms not only with the direct effects of the head injury, but also with the resultant changes in their relationships with the injured person. The effects of head injury are not time limited,

either. They persist for the head injured persons entire lifetime.

The already high levels of stress experienced by families in lower socioeconomic groups is multiplied by the incidence of head injury. Given the large numbers of people who receive head injuries each year in New Zealand, it is safe to say that there are many very stressed families in the community who are coping with extremely high burdens on a daily basis.

Brooks (1984) identified some common questions that permeate the literature concerned with the psychosocial aspects of head injury. These include the following:

1. What are the main features of psychosocial disability and family burden?
2. Can the severity of such disability and burden be predicted by the severity of the injury?
3. Which type of family relationship is most vulnerable?
4. How satisfied are relatives with the communication and information that they have received from professionals dealing with the patient?
5. What is the role of premorbid factors in predicting post-traumatic psychosocial disability?
6. How does such a disability change during the first five years after injury? (Brooks, 1984, p 124).

The issues to be addressed in this section of the literature review are the first and third issues identified by Brooks (1984).

### Consequences of Head Injury

This section covers the general course of recovery. It also looks at a number of disabilities that may result from head injury.

## Recovery and Outcomes

There is general agreement in the literature about the course of recovery from severe head injury. The initial part of recovery takes place over the first six months after injury and involves the recovery of physical and mental functions directly attributable to brain function (Bond & Brooks, 1976, cited in Bond, 1986; Bond, 1983).

### Family Perceptions of Recovery

The initial recovery period is characterised by the person showing great improvement. Following this the rate of improvement slows. This can create difficulties for families, who, because of the initial recovery rate, may expect that it will continue, enabling their loved one to attain full recovery within a reasonably short time. This is abetted by unfamiliarity with irreversible disease. The family may expect someone who is 'sick' to eventually become well (Lezak, 1978). Thus, the idea of their loved one having a lower level of functioning than before the accident or illness is completely alien and not readily accepted.

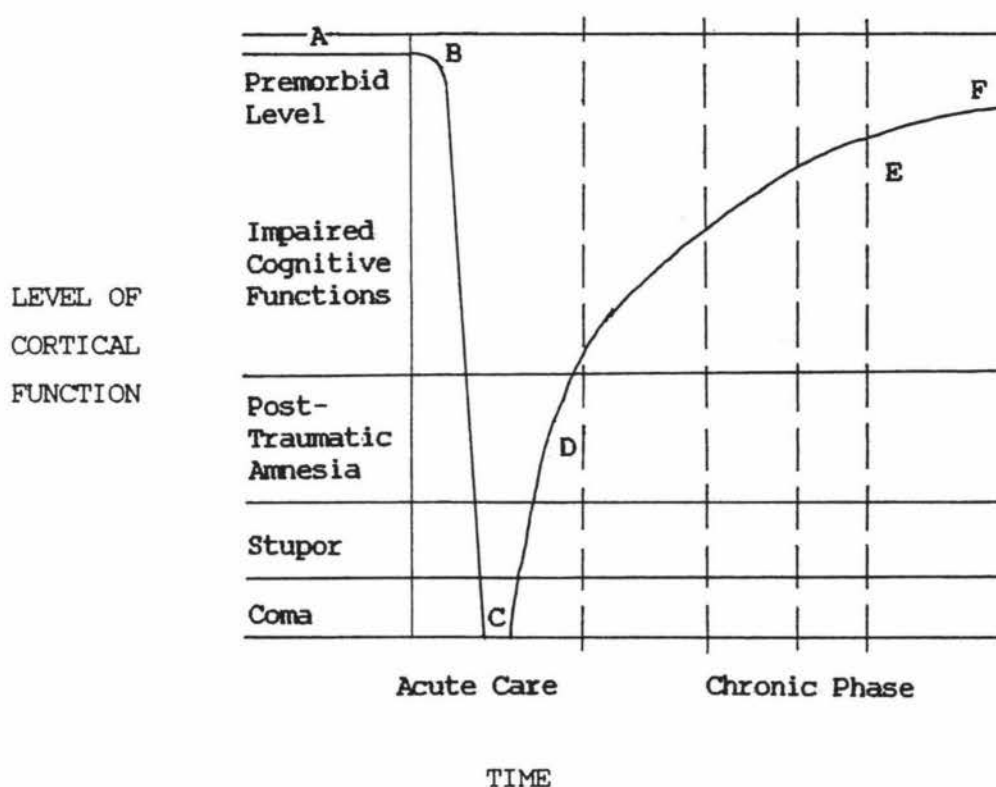
These unrealistic but understandable expectations often held by family members can compound the stress a family faces as a result of the changes that will have occurred in the person with head injury (Lezak, 1986). Such expectations are enhanced by a number of factors, including the high rate of early recovery already mentioned.

These factors include the terminology used by the clinicians dealing with the person with head injury. When clinicians use the term 'recovery', they are often referring to 'improvement', rather than 'return to normal', as is assumed by the family (Lezak, 1986). This is often not explained to the family, so this misguided notion continues.

Another factor that makes it difficult for the family to see that the head injured person has changed is the fact that often, his/her physical appearance remains unchanged. There are no obvious outward differences to indicate that the person has changed. Families tend to respond to the person they remember, rather than to the person who is in front of them (Lezak, 1986), who may not react in the ways the family expect. This is also bound up in the denial process that often accompanies grieving.

That incomplete recovery is often the case is illustrated by Long, Gouvier and Cole's (1984) model of recovery from head injury, which provides a concise summary of the process. This model is illustrated in Figure 1 (Page 8).

The stages of recovery illustrated in Figure 1 have also been conceptualised by Bond (1986) as consisting of three main phases. The first aspect or stage is that of neurological recovery. Following this is a more general adaptive process, the gradual adaptation to primary mental and physical deficits (Bond & Brooks, 1976). The final stage of recovery is a social process involving interactions with those closest to the person with head injury and resultant adjustments to their social status.



**Figure 1:** Diagrammatic representation of level of cortical functioning as a function of time since head trauma (A = premorbid level, B = retrograde amnesia, C = coma and/or stupor, D = post-traumatic amnesia, E = impaired cortical functioning, and F = level of recovery) (Long et al, 1984, p 63).

Difficulties for the family not only arise when the person's rate of recovery slows, but when he/she gets home. This is because subtle changes in personality, memory and intellectual functioning are not readily apparent during the acute phase of recovery (Long et al, 1984), and personality changes are often more prevalent when the person returns home (Blyth, 1981). The 'sudden' appearance of such changes may be due to the fact that the assessment procedures used may not pick up such changes. For example, changes in communication are often only readily apparent in free conversation rather than in structured language tests (Bond, 1986). The family also may be more sensitive to changes of this nature in the person.

There has been a great deal of agreement between research studies in this area regarding the outcomes from head injuries, especially those concerned with psychosocial outcome (Brooks, 1984). The vast majority of people suffering severe head injuries show some form of marked psychosocial deficit. Such problems can include memory deficits, behavioural changes, personality changes, emotional instability, and difficulties with learning, to name a few. The exception to these findings are the studies conducted by Oddy, Humphrey and Uttley (1978b, 1980), which report that closed head injury resulted in only minor social disability with minimal disruption to work, social contacts and family life as assessed six months after injury. A number of differences between this research and other studies in this area have been noted by several authors (eg, Bond, 1986; Brooks, 1984; McKinlay, Brooks, Bond, Martinage & Marshall, 1981). These differences include the greater proportion of subjects in the studies by Oddy et al who had Post-Traumatic Amnesia (PTA) of less than one week and who came from middle and upper socioeconomic classes. Both of these factors are linked to less severe disabilities resulting from head injury.

## Disabilities

Brooks, McKinlay, Symington, Beattie and Campsie (1987) conceptually divided the disabilities resulting from head injury into three categories: physical, cognitive and behavioural/emotional. These three categories will be used here to illustrate some of the effects of severe head injury although these three domains overlap.

### Physical Disabilities

The physical disabilities that may arise from head injury are numerous, and their extent and severity depend on a number of factors (eg age, pre-traumatic physical state, site and extent of damage). They may be a consequence of the head injury itself, such as visual problems

(Brooks, Campsie, Symington, Beattie & McKinlay, 1986; McKinlay et al, 1981; Crawford, 1983; Rimel & Jane, 1983), gait disturbances (Thomsen, 1974; McKinlay et al, 1981), other motor disturbances (McKinlay et al, 1981; Thomsen, 1974), hemiplegia or hemiparesis (Crawford, 1983; Thomsen, 1974; Newman, 1984; Oddy et al, 1978b), and epilepsy (Crawford, 1983; Newman, 1984; McKinlay et al, 1981). Physical disabilities may also be a result of other injuries sustained. If the head injury was incurred through an accident, the most common seems to be orthopaedic injuries (Oddy & Humphrey, 1980; Rimel & Jane, 1983).

Jacobs (1988) found that physical impairments resulting from head injury led to a lessened ability to function independently around the home, decreased stamina, problems with basic self care, and interfered with education by making attending school difficult.

It is generally agreed that physical disabilities are not the main source of stress for the relatives of people with head injuries (Thomsen, 1978; Brooks, 1984; Brooks et al, 1987; Crawford, 1983; McKinlay et al, 1981; Panting & Merry, 1974).

### Cognitive Disabilities

According to the literature reviewed, there are a number of areas of dysfunction that are classified as 'cognitive'. These include such specific areas as memory, language and communication, intelligence, the ability to learn new material, speed of information processing, and thinking and reasoning in general.

#### *Factors Influencing Cognitive Disability*

A variety of factors may affect the degree and nature of cognitive disability that may result from head injury. Obviously the severity of the injury has considerable influence. The length of Post-Traumatic Amnesia seems to be the most reliable indicator of injury severity that

is related to degree of cognitive dysfunction (Brooks et al, 1980, cited in Bond, 1986). Bond (1975, cited in Bond, 1986) concluded that the duration of Post-Traumatic Amnesia was related to the levels of social, physical and mental disability, and that patients with a period of PTA greater than 4 weeks would be disabled in all three areas to some extent. Glasgow Coma Scale ratings (GCS) seem to bear little relation to cognitive outcome (Brooks et al, 1980, cited in Bond, 1986). Thus, in general, the more severe the injury, as indicated by the length of PTA, the greater likelihood of more severe cognitive impairment. Severity of injury, however, is not related to rate of recovery, only to its final level (Groher, 1977, cited in Bond, 1986).

The age of the head injured person is also an important factor in determining outcome. It has been found that those injured in childhood or adolescence usually show considerable improvement of intellect, because their recovery is assumed to combine with the normal development of the brain (Bond, 1984). Persons becoming head injured after 30 years of age show relatively little improvement after two years following injury, but do make gains prior to this (Bond, 1984).

The type of injury can also determine the probability of cognitive impairment. Closed head injuries are characterised by diffuse subcortical damage, which is often associated with memory difficulties. The focal damage associated with other forms of brain insult is less likely to result in memory impairment (Bond, 1986).

#### *Effects on Cognition - Memory*

The resultant effects of head injury on cognition can be extremely widespread. Memory difficulties are the most frequently reported of the cognitive disturbances (Bond, 1986), and take the greatest time to recover (Brooks and Aughton, 1979, cited in Bond, 1986). Crawford (1983) found that of a sample of 50 people with head injuries, 28 had memory difficulties. McKinlay et al (1981) found that relatives most consistently reported the person with head injury's memory impairment

as a cause of difficulties. According to Bond (1984), however, memory difficulties do tend to improve over time, although final levels tend to be lower than before the injury.

#### *Effects on Cognition - Learning*

Related to memory impairment are the difficulties experienced by many people with head injuries in learning new material or recalling information stored before the injury (Bond, 1986). The deficit in recall is the most obvious in everyday life (Bond, 1986). Brooks et al (1986) found that the most common memory difficulties reported by relatives of people with head injury were: the person forgetting what they were doing in the middle of an action sequence, repeating or double checking actions and losing track of what they were saying. Memory difficulties contribute to impaired ability to profit from experience. This lessens the capacity for social learning (Lezak, 1978), with all its attendant implications for everyday life.

#### *Effects on Cognition - Language and Speech*

Substantial difficulties with language and speech are generally uncommon after closed head injury, and tend to recover well if present (Bond, 1986). Broad communication difficulties arise from the combination of speech/language impairments and multiple cognitive deficits that hinder communication in general (Groher, 1983, cited in Bond, 1986). The recovery time for these deficits varies between people, but most recovery from aphasia seems to occur within six to nine months of injury (Bond, 1986). Recovery seems to follow a general pattern, with visual and auditory comprehension recovering first, followed by expression and writing (Najenson, 1978, cited in Bond, 1986). Jacobs (1988) found that in his sample, people with head injuries were reported by their families to understand the communication of others better than they could communicate themselves. McKinlay et al (1981) also found similar results, with word finding and fluency being the areas of communication in which the greatest

difficulties were found.

#### *Effects on Cognition - Information Processing*

As a result of head injury, general intelligence and speed of information processing may also be affected. Mandleberg and Brooks (1977, cited in Bond, 1986) administered the Wechsler Adult Intelligence Scale to 40 adults with severe brain injuries. They found that the scores on the verbal subtests were less impaired initially and recovered faster than nonverbal subtest scores. It was concluded that this may be due to characteristics of the test, rather than the effects of the injuries themselves. Obviously a more suitable diagnostic tool is necessary for assessment in this area. Slowed information processing has been noted by a number of authors as an effect of closed head injury (Bond, 1984; Bond, 1986; Long et al, 1984), and is thought to be a result of structural damage within the brain (Bond, 1986).

Oddy and Humphrey (1980) found that poor performance on certain cognitive tests (the Inglis Paired Associate Learning test and the Wechsler Logical Memory test) was significantly ( $p = 0.05$ ) related to limited social contact. Possibly related to this are the difficulties experienced as a result of memory impairment in terms of the person with head injury not being able to be left alone, because they may in fact be a danger to themselves or others. This may, in combination with emotional/behavioural difficulties, severely limit their social contacts, at least until the degree of memory impairment has stabilised.

#### *Effects on Cognition - Lack of Awareness*

A further effect of cognitive deficits is the head injured persons seeming denial of, or lack of awareness of any serious residual problems, which Brooks (1984) states is a common finding in this area. For example, Fahy, Irving and Millac (1967, cited in Brooks, 1984) found marked differences in the reports of the presence of symptoms

between the people with head injury and their relatives. The head injured people "often denied or 'lightly dismissed' any disabilities, and spontaneous complaints by patients were rare" (Brooks, 1984, p 125), while the relatives gave detailed accounts of various difficulties, including cognitive deficits. While the disparities between the accounts given by people with head injuries and their relatives can be regarded in terms of denial as an ego-protective strategy, it is also obvious that neurologically-based information processing deficits can also manifest themselves in this way (Prigatano & Fordyce, 1986). In fact, unrealistic self-appraisal can be a major issue following head injury, and it has been theorised that this is due to an underlying "state of generalised cortical hypoarousal and an accompanying diminished alerting or orienting response to novel stimulation" (Bear, 1983; and Heilman, 1979; cited in Prigatano & Fordyce, 1986, p 13).

#### *Effects of Cognitive Disabilities*

Two areas discussed in the literature that are affected directly by cognitive disabilities resulting from head injury are the return to work of the head injured person and the burden on their family. The literature on these two areas is discussed briefly here.

#### *Effects of Cognitive Disabilities - Return to Work*

Return to work has been found to be affected by cognitive disabilities resulting from head injury (Fahy, Irving & Millac, cited in Oddy, 1984). Oddy and Humphrey (1980) found that people who had suffered head injury who returned to work had altered capabilities within their jobs, and a reduced ability to work. Brooks et al (1987) found that memory difficulties were a significant predictor of problems in returning to work. This seemed to involve a general memory deficit rather than any specific difficulties. Communication difficulties are also related to the inability to return to work. Specifically, Brooks et al found that two specific deficits were most important in this,

namely deficits in carrying on a conversation and understanding a conversation. It was found that the presence of these deficits was a good predictor of failure to return to work. However, the absence of these deficits did not guarantee return to work. This illustrates the multidimensional nature of communication problems resulting from head injury. This also mirrors the fact that subtle communication difficulties may not be picked up in the structured testing situation, but become evident and extremely important in everyday conversation, either in the home or in the workplace.

### *Effects of Cognitive Disabilities - Family Burden*

In terms of burden or distress to relatives, cognitive deficits can be seen to be more of a problem than physical disabilities (Thomsen, 1974), with a high degree of mental disability being associated with a high degree of disruption of family cohesion (Bond, 1975, cited in Brooks, 1984). The greatest issue for families is the change in personality that often accompanies severe head injury. Such changes may be a combination of many factors, including cognitive deficits, giving the overall impression that the head injured person is not the same person as they were before their accident.

### Behavioural/Emotional Changes

There is a high degree of agreement in the literature concerned with the effects of head injury that behavioural/emotional changes in the head injured person constitute the greatest source of difficulty and distress for the family (Thomsen, 1974; McKinlay et al, 1981; Brooks et al, 1986; Panting and Merry, 1972; Lezak, 1978; Brooks & McKinlay, 1983; Blyth, 1981). There is also general agreement regarding the behavioural-emotional changes that can result from severe head injury. These behavioural-emotional changes have also been given the less specific label of 'personality changes', and the two terms are used interchangeably here. A large number of such changes have been noted

by various researchers, and a selection of these is outlined here. These changes have been loosely grouped under the following headings: Emotional And Behavioural Control and Expression; Motivation; Relating to Others; Psychopathological Symptoms; Frontal Syndrome; Positive Changes; Primary and Secondary Change; and Catastrophic Reaction. Some changes listed can be classified in more than one way.

#### *Emotional and Behavioural Control and Expression*

Changes noted in this area include a lack of self confidence and low self esteem (Bigler, 1989), childish behaviour (Crawford, 1983; Blyth, 1981; Brooks & McKinlay, 1983) and a lowered tolerance for frustration (Bond, 1984). One of the most commonly noted differences following head injury centres around the ways in which anger is handled. Bad temper (Bigler, 1989; Blyth, 1981; Bond, 1984; McKinlay et al, 1981; Brooks et al, 1986; Brooks & McKinlay, 1983), aggression (Crawford, 1983; Bond, 1983) and irritability (Blyth, 1981; Bond, 1983, 1984; McKinlay et al, 1981; Brooks et al, 1986; Brooks & McKinlay, 1983; Crawford, 1983; Lezak, 1978) are all commonly noted. This may be coupled with a lowered tolerance for frustration (Bond, 1984) and an impaired capacity for control and self regulation, leading to impulsivity, restlessness and impatience (Lezak, 1978; Bond, 1983; McKinlay et al, 1981).

Other changes that may be included under this heading are changeability and mood fluctuations, as noted by Bond (1984), Brooks and McKinlay (1983) and Lezak (1978). Increased levels of anxiety (Bond, 1983; McKinlay et al, 1981; Brooks et al, 1986) and depression (McKinlay et al, 1981; Crawford, 1983; Bond, 1984) have also been documented.

#### *Motivational Changes*

Changes that have been noted in the head injured person's motivation include lowered drive and energy levels (Bigler, 1989; Crawford, 1983), lowered self reliance (Brooks & McKinlay, 1983), and apathy (Bond,

1983; Lezak, 1978).

### *Relating to Others*

A number of changes in the ways in which the head injured person relates to others have been noted by a number of authors. These changes include a lack of judgement and consideration for others (Blyth, 1981), self-centred behaviour, and a decrease in empathy and self-reflection (Lezak, 1978). Lezak (1978) notes that these changes may have their origins in cognitive impairment, which results in a decreased capacity for social perceptiveness. Changes in the person's sexual appetite have also been documented (Lezak, 1978).

### *Psychopathological Symptoms*

In some cases, psychopathological symptoms may follow severe head injury. Bond (1984) notes that in association with irritability, impatience and lowered tolerance for frustration, suspiciousness and sometimes paranoid delusions may develop. Cognitive changes may be associated with the development of "organic orderliness" (Bond, 1984, p 159). This manifests as high levels of orderliness in thinking and everyday activity, which is reminiscent of the symptoms of psychiatric patients with obsessional neurosis. The development of this behaviour is said to arise out of the need of the person to retain a sense of control over their thinking and the events around them (Bond, 1984).

### *Frontal Syndrome*

One of the best known and well documented disorders of emotion, behaviour, and more variably, cognition, due to brain injury is the Frontal Syndrome. This syndrome was first studied and documented by Harlow (1848 - 1868, cited in Kolb & Whishaw, 1985)) in his study of Phineas Gage. Since then a number of typical features of the frontal syndrome have been identified. Disinhibition and loss of insight seem to be the central criteria for determining the severity of the disorder

and are more or less common to all manifestations of the syndrome (Bond, 1984). People suffering from this syndrome may show evidence of facile euphoria, blunting of emotional responsiveness, egocentricity, interference with others' behaviour, irresponsibility, lack of tact and concern, childishness, purposeless drive, and loss of judgement (Bond, 1984). Some may show apathy and inertia, while others may be aggressive (Bond, 1984). Changes may be evident in the person's sexual behaviour, which may either be reduced or become promiscuous. Two patterns of personality changes have been identified in people with the Frontal Syndrome - "pseudodepression and pseudopsychopathic" (Blumer & Benson, 1975, cited in Kolb & Whishaw, 1985) - both of which consist of different combinations of the symptoms listed above.

#### *Positive Changes*

Not all of the changes noted as a result of head injury are negative, however. The person with head injury may undergo welcome changes in personality and behaviour (Fahy et al, 1967, cited in Brooks, 1984; Blyth, 1981). They may become closer to the rest of their family, more affectionate (Weddell, Oddy & Jenkins, 1980), more attentive to them, possibly through an increase in dependence on their relatives.

#### *Primary and Secondary Change*

The distinction needs to be made here between primary and secondary emotional-behavioural changes. Primary and secondary changes have been mentioned previously, with respect to recovery and outcome. Primary changes are "mental changes directly attributable to damage or destruction of brain tissue, especially when injuries are severe" (Bond, 1984, p 148). Secondary changes are the person's reactions to the primary effects of their injuries (Prigatano, 1986), and as such, may be said to include the more emotional changes that are seen after head injury (Bond, 1983). It can be seen that the primary effects of head injury interact with the secondary effects to produce behavioural-emotional changes in the person. For example, as Lezak (1978) points

out, "self awareness without insight and distorted by defective social awareness may give rise to ...paranoia" (p 592), where defective social awareness is a primary result of head injury. Another example of this interaction may be found in the fact that memory impairments may show large variations as a function of depression or low motivation.

### *Catastrophic Reaction*

A further example of a commonly found behaviour pattern that may be classified as a secondary effect is the Catastrophic Reaction (Goldstein, 1952, cited in Prigatano, 1986). The Catastrophic Reaction is said to be associated with failure to cope, and overtly manifests itself as severe anxiety. People with head injuries can be easily threatened and experience an associated anxiety about life because of their decreased abstract reasoning skills. Many of these people have a "strong need to discharge this tension or anxiety and frequently do so without the social amenities" (Prigatano, 1986, p 34). This may be one of the reasons for their being labelled as being impulsive, behaving inappropriately, and being psychologically unsophisticated (Prigatano, 1986). Because these actions have a reinforcing effect, in that they provide a discharge of tension, but also bring about punitive reactions from others around them, the person's feelings of confusion and inadequacy may be added to (Prigatano, 1986).

Thus, secondary changes may, in addition to their singular effects, have further negative effects on other activities that may have already been compromised by the head injury (Bond, 1983).

### *The Role of Pre-Traumatic Personality*

The role of the head injured person's pre-morbid personality in post-traumatic personality changes has been discussed by a number of authors over a long period of time. It is obvious that people incurring head injuries are not a random sample from the general population. As a group they have a number of characteristics that may or may not be

causally associated with the incidence of head injuries. Some of these demographic characteristics were outlined in an earlier section of this report (see 'Context'). The personality characteristics of this group, while less well-known, have been hinted at. For example, many people with head injury have been in trouble with the law prior to their head injury; many showed evidence of antisocial behaviour and had unstable family lives, poor school records and a lack of marital stability (Jamieson, 1971, cited in Brooks, 1984).

A number of authors have made broad statements regarding the effects of premorbid personality on post-traumatic outcomes. Generally, these indicate that, in all but those most seriously injured (Prigatano, 1986; Bond, 1984) pre-traumatic personality traits are evident and often exaggerated during and after recovery, and influence post-traumatic disability (Bond, 1984). For example, Panting and Merry (1974) found that post-injury attacks of emotional rage were more likely in people with pre-morbid personality instability than in those with more stable personalities, although personality instability was not clearly defined.

This claim would seem reasonable given the extremely complex nature of personality and its possible interactions with primary brain damage and responses to the resultant disabilities (Bond, 1984). However, this point is extremely difficult to empirically demonstrate (Prigatano, 1986) and conclusions have, more often than not, been based on intuition and judgement, rather than hard data (Brooks, 1984). This area, therefore, obviously needs further and more thorough investigation. The possible influence of pre-morbid personality characteristics should, however, not be ruled out because of lack of hard research evidence.

#### *Differences in the Pattern of Personality Changes Over Time*

Differences have been noted in the patterns of behavioural and personality changes over time. Brooks et al (1986) noted that

relatives most frequently reported personality change after five years, its frequency increasing from 60% at one year, to 74% after five years. Reports of depression also increased from 51% to 57%. The greatest increase noted in these two consecutive studies was in reports of threats of violence, which rose from 15% after one year, to 54% after five years.

### **Family Burden**

As previously stated, there is wide agreement that it is the behavioural-emotional and cognitive changes in the head injured person that are the most stressful for family members. The nature of the burden experienced by families has not been widely documented. The main focus in the literature has, until recently, been on the outcome for the head injured person after injury. A few studies concerned with the stress and burden experienced by families are reviewed here. A number of studies have attempted to examine this area in more detail, focussing on the aspects of the changes that are the most stressful for relatives of people with head injuries. These too are examined briefly.

Lezak (1978; 1986) has proposed that most families undergo a series of reactions as their understanding and appreciation of the changes in the head injured person increases. She has conceptualised these reactions into six stages, which are summarised in Table 1 (Page 24).

These stages tend to overlap and may be experienced in a different order or at a different rate from that indicated here. Some stages may be missed altogether, or a family may become stuck in one stage (Lezak, 1986). During the initial stage, when the person returns home, the family are pleased and so involved with helping him/her that they may not notice any differences (Lezak, 1986). This may be termed the 'honeymoon' stage. Stage two is a period of anxiety and bewilderment. The family feels that something is different but cannot say what it is,

and their optimism and energy start to weaken. This stage precedes family members' appreciation of the chronicity of the changes that have taken place (Lezak, 1986).

The third stage often develops when, regardless of the family's attempts to improve it, the situation worsens. The family often start to realise at about this stage that there are, in fact, a number of changes that have taken place that are not going to disappear. This takes place in conjunction with the head injured person's attempts to resume pre-trauma activities and the crystallisation of their inappropriate behaviours into habitual responses (Lezak, 1986). Once the family has struggled through the realisation that the person's personality has been permanently changed by their injury, they may enter the fourth stage. In this stage, family members come to understand that they, as individuals, are not responsible for the distress experienced by the family and that the head injured person is probably not going to make very much more improvement (Lezak, 1986). Stage five is the period of active mourning. The family gives up all hope that the person will return to their former selves, and the difficult and often drawn-out process of mourning for a living person commences.

The final stage of this process involves the family reorganising their lives to allow for maximum growth and satisfaction for all (Lezak, 1986). Emotional and/or physical detachment may be decided upon as the best option for some family members.

**Table 1:** Stages in the evolution of family reactions to a brain-damaged member (Lezak, 1986, p 244).

Stage	Time Since Hospitalisation	Perception of Patient	Family Expectation	Family Reaction
I	0 - 1 to 3 months	A little difficult because of fatigue, inactivity, weakness, etc	Full recovery by one year	Happy
II	1 - 3 to 6 - 9 months	Not co-operating, not motivated, self-centred	Full recovery if he'll try harder	Bewildered anxious
III	6 - 9 to 9 - months; can continue indefinitely	Irresponsible, self-centred, irritable, lazy	Independence if know how to help him	Discouraged, guilty, depressed, going crazy
IV	9 months or later; can continue	A different, childlike person	Little or no change	Depressed, despairing "trapped"
V	15 months or later; usually time limited	A difficult, childlike dependent	Little or no change	Mourning
VI	18 - 24 months or later	A difficult, childlike dependent	Little or no change	Re-organisation - emotionally if not physically disengaged

### Outcomes of Research Into The Effects of Stress on Relatives

Several studies have examined the nature of the stress experienced by relatives of people with head injury, and, although the extent of the stress-related effects varies between studies, there is general

agreement that caring for or living with a partner or relative who is head injured can have definite effects on physical and psychological well-being.

### Psychological and Psychiatric Dysfunction in Relatives

Evidence has been found of relatives and partners suffering from depression, anxiety, and showing signs of psychiatric dysfunction. Using the Wakefield Scale to assess depression, Oddy et al (1978a) found, not surprisingly, that one month after the accident, 39% of relatives had scores that indicated they were suffering from depression. At the six and twelve month follow-up periods this had dropped to 20% and 23% respectively.

This study showed that depression in relatives was not significantly related to Post-Traumatic Amnesia, length of hospitalisation, or social recovery in terms of degree of social contact. There was, however, a significant negative correlation between relatives' depression and the time taken for the head injured person to return to work. However, this was found only when the seven people in the study who did not return to work within 12 months were included in the analysis. Thus, greater levels of depression in relatives have been found to be associated with lower levels of social recovery in people with head injury, as indicated by the time taken to return to work.

A significant relationship was found by Oddy et al between relatives' depression and two specific personality changes in the head injured person, namely confusion and verbal expansiveness. Depression was also significantly related to the relatives' subjective ratings of the number of symptoms experienced by the head injured person.

Rosenbaum and Najenson (1976) also found that the wives of men with head injury in their study reported a number of symptoms of depression. A behavioural approach was used to operationalise these findings and

stated that these women were performing more tasks and activities (both within and outside the home) and were receiving less positive reinforcement for this.

Livingston, Brooks and Bond (1985a & b) assessed the psychiatric and social functioning of female relatives (wives, mothers and in three cases, daughters) of men with severe head injuries, compared to that of relatives of men with mild head injuries. They found that a significant proportion of relatives of severely head injured men suffered from psychiatric disturbance as measured using the General Health Questionnaire and the Leeds Depression and Anxiety Scales.

Their results differed from those of Oddy et al (1978a) in that, while this disturbance was primarily affective, it was anxiety-based rather than depressive. This was so for the three, six and twelve month follow-up periods. Three months after the accident, 45% of the relatives of men with severe head injuries had Leeds Anxiety scores that were beyond the 'caseness' threshold for that measure. The term 'caseness' refers to the level of anxiety at which "clinically significant psychiatric disturbance is likely to be present" (Livingston, 1987, p 34). At six and twelve months, these levels had dropped to 37%. According to the GHQ scores, at the three month follow-up (Livingston et al, 1985a) there was a significant difference between the two groups in terms of the anxiety/insomnia and social dysfunction subscales of the GHQ, reflecting differences in the ability to cope between the two groups. Forty percent of relatives of severely head injured men at three months, 37% at six months, and 28% at twelve months were above the 'caseness' threshold on the GHQ. While these figures show a marked decrease over time, which is perhaps not surprising, the fact still remains that over a quarter of the relatives surveyed were experiencing substantial psychiatric dysfunction in terms of coping and anxiety. That this dysfunction is persistent may indicate that these relatives were faced with continual stress throughout the year of the study (Livingston et al, 1985b).

### Social Functioning in Relatives

The social functioning of relatives of men with severe head injuries was also found by Livingston et al (1985a & b) to be compromised. They found a significant difference in social functioning between relatives of mildly and severely head injured men, with the severely injured men's relatives being worse off. Social functioning (as measured using the Weissman Social Adjustment Scale), tended to worsen from three to six months after the accident, and then remain at about the same level to the twelve month follow-up period. At the three month follow-up, problems in social functioning were generally confined to roles within the family home, with marital and family unit functioning being significantly worse for the severe group. At six and twelve months after the accident, functioning in all social roles was found to have worsened. Marital functioning once again worsened in particular, although it was not stated whether this included only the wives of the severely head injured men or all of the relatives questioned. Similar results were found by Livingston (1987) in his investigation of relatives' psychosocial response to severe head injury.

### Effects on the Physical Health of Relatives

Physical health has been found to be altered in relatives of people with head injuries, although the figures given for the extent of these effects vary widely. Panting and Merry (1974) state that 61% of the wives and mothers of people with head injury that they surveyed needed supportive treatment in the form of "tranquilizers and sleeping tablets" (p 35) whereas Oddy et al (1978a) found that six and twelve months after the accident 25% of relatives reported illnesses over the preceding six months, most of which were classified by the authors as being psychosomatic and emotional.

The abovementioned studies provide a descriptive picture of the possible effects on the relatives' health of living with a person with

head injury. Several studies have attempted to link such effects with specific issues and factors that are important in the lives of people in this position.

### Cause and Effect Relationships in the Stress Experienced By Relatives

#### *Perceived Burden and Consequences of Head Injury*

McKinlay et al (1981) and Brooks et al (1986) examined the relationship between a general measure, 'subjective burden experienced by relatives', and seven 'problem areas' in the head injured person experienced by the relatives. These include physical, language, emotional, dependence, subjective, memory and disturbed behaviour. The changes in both perceived burden alone, and in its relationship to these problem areas over time were also examined.

Over the five years these two studies covered, the pattern of perceived burden changed markedly. One year after the accident, 43% of the relatives interviewed stated that they were experiencing low burden. By the five year follow-up, this number had dropped to 10%. The percentage of relatives experiencing high burden, however, had risen from 24% at one year, to 56% at five years. Only two of the ten relatives with high burden at one year had experienced a decrease in burden.

McKinlay et al (1981) found that changes in emotion, disturbed behaviour, and subjective changes were all significantly associated with differences in the low, medium and high burden groups at the three, six and twelve month follow-up periods. This supports the general idea that behavioural and emotional problems or changes in the head injured person are associated with greater burden in their relatives. When the five year follow-up was carried out, it was found that more of these areas of difficulty were associated with burden. Language changes and dependency had also become important by this time. Thus, as the number of factors defined as problematic had increased,

so had the burden experienced by relatives.

Brooks and McKinlay (1983), in their investigation of the nature of personality change following severe head injury, examined the relationship between perceived burden and personality change specifically. They found that the presence of personality change per se was not a guarantee of greater perceived burden by relatives, and that the relationship between these two variables was less straightforward. Their results showed that if personality change was present, then relatives may or may not report high burden. However, if high burden was reported, then the probability that the head injured person will be judged to have personality change is very high (92%), and this probability may increase over time.

The relationship between personality change and family burden was also found to change over the year covered by the study. At the three month follow-up, only one measured aspect of personality had changed significantly in the high burden group (ie being self reliant had changed to relying on others). At the six and twelve month follow-up periods this factor had disappeared to be replaced by eight factors at six months, and a further four factors at twelve months. A year after the accident, therefore, "a wide variety of features in the patient (sic) had become associated with High Burden in the relative, including control of emotion, ... reduction in energy, ... immaturity, emotional coldness, unhappiness, cruelty, meanness, and unreasonableness" (Brooks & McKinlay, 1983, p 343). This finding mirrors that of Brooks et al (1986), that over time, more areas of change become associated with greater perceived burden by relatives.

#### *Personality Change and Family Friction*

Weddell, Oddy and Jenkins (1980) also examined the association between personality change and another general factor - that of friction within the family. They also did not find a straightforward relationship between the two variables. Their results indicated that, when the

group of families of people with head injuries was divided into head injured people with an increase in irritability versus those without such an increase, greater friction was found in the former group of families. Thus, Weddell et al associate increased family friction with the presence of a particular personality change, namely increased irritability. This particular change is widespread among those with moderate to severe head injuries (Crawford, 1983; McKinlay et al, 1981; Brooks et al, 1986), which would seem to indicate that increased family friction may be fairly common in this situation.

#### *Marital Difficulties and Consequences of Head Injury*

Peters, Stambrook, Moore and Esses (1990) examined the relationship between marital difficulties and a number of factors relevant to head injury. They found that factors such as severe injury, high psychosocial maladjustment of the head injured person, restricted day to day functioning and financial burden were prominent in predicting marital maladjustment. They hypothesised that these variables are present and must be confronted on a day to day basis, and therefore will have a high degree of impact on the spouse of the person with head injury, leaving them overwhelmed and vulnerable to stress. Peters et al also made a comparison of the effects on marital adjustment between wives of mildly, moderately and severely injured men. Their results indicated that the wives of the severely injured men experienced more difficulty and disagreement in reaching joint decisions, less overt acts of verbal or physical affection between themselves and their spouses, and had overall lower levels of marital adjustment than the wives in the other groups.

Overall, it can be seen that living with a relative with head injury can have serious effects on both psychological and physical well-being, although this relationship is not a straightforward one. Common effects on individual relatives seem to be anxiety, depression, and psychosomatic complaints. Families of those people with head injury who experience personality change that includes increased irritability

are likely to experience greater friction. This is likely to be a large proportion of families of people with head injury.

People with head injuries who return to their families and feel supported by them tend to function better in the long term than those who are not supported by their families. For this reason, it is extremely important for families to have support themselves, in order to counteract the effects of having a head injured relative. This has serious implications on a number of levels. Firstly, such support impacts on the way in which the family functions and therefore supports the head injured person. In turn this influences the prognosis for the head injured person. This also has economic implications in terms of the amount of follow-up assistance, both short- and long-term, and crisis intervention needed by both the head injured person and their family.

#### Vulnerability of Marital and Parental Relationships

The literature concerned with the relative vulnerability of different types of relationships to the strain placed on them by the incidence of head injury is both sparse and equivocal. It is sparse both in terms of the number of studies that have addressed this issue, and in terms of the lack of significant research into, and concentration on the area. Most of the studies that actually address this issue do so as a sideline to other research. Rarely is the vulnerability of various relationships the primary focus of research studies to date. Also, when this area is examined, seldom are there enough participants to enable any significant inferences to be made about the vulnerability of certain relationships. This may be due to several factors, for example the tangential nature of such research. Thus, while the participant numbers are large enough to examine the primary research questions, the sizes of the parent and partner groups are often not big enough for such research when they are separated. The reportedly high separation rate of married couples after head injury

(eg Crawford, 1983; Panting & Merry, 1974) may also partially account for the small numbers of partners taking part in research.

With these limitations in mind, a number of studies that have in some way concerned themselves with this area will be reviewed in order to give an indication of the current state of thought regarding this area of research.

The literature can be divided into several areas. A number of studies have found that partners experience more stress than parents, while some authors would assert the opposite. Several authors found no difference between the two, while some found qualitative, rather than quantitative differences.

#### **Research Outcomes Indicating Greater Levels of Stress In Marital Relationships**

The case for partners experiencing more stress than parents, and therefore the marital or partner relationship being more vulnerable than the parental relationship is put forward by a number of authors. It is, however, backed up with very little empirical evidence (Peters et al, 1990). This is shown in the claim made by Blyth (1981) that the personality changes experienced as a result of head injury are more damaging for married couples than for parents who seem to demonstrate more stability in coping. Panting and Merry (1974) also found that the husband-wife relationship was less stable under the stress generated by head injury than a parent-child relationship. Thomsen (1978) indicated that in her study, mothers of people with head injury were able to accept the changes in their son/daughter's behaviour, but few of the spouses were able to do so. It is notable that in all of these assertions, the methods by which such results were achieved are not given.

Livingston (1987) and Livingston et al (1985a & b) investigated the

psychosocial impact of head injury on wives and mothers of head injured men in terms of their psychiatric and social role functioning three, six and twelve months after their husbands'/sons' accidents. All three studies found that at the three month follow-up, marital functioning had deteriorated the most out of all of the social roles assessed, and that this deterioration continued to the six month follow-up, and from then to the twelve month period reached a plateau. Unfortunately, none of these studies broke down these figures to show whether this deterioration was greater in the marital relationships of parents of people with head injury, or in the relationship between a head injured person and their partner.

A number of researchers have examined the rate of marital or relationship separation as an index of marital strain. Crawford (1983) states that of the eighteen couples in his study, two marriages had broken up, and four were on the verge of separation. This gives a separation rate among couples of thirty-three percent. Panting and Merry (1974) also examined marital separation, and found that of the ten couples who were married at the time of the accident, three had subsequently divorced and one had separated, giving a rate of separation of forty percent. There are several problems with these figures and with making assumptions from them. Firstly, they are based on extremely small numbers, making extrapolations somewhat unreliable. Secondly, there is no indication as to whether the marriages that had broken up were under strain before the accident. And finally, divorce or separation is not necessarily a good indicator of stress or dissatisfaction within the relationship. As Lezak (1978) points out, there are many reasons why a person may feel that they cannot leave their head injured spouse, and yet they may be extremely unhappy and the relationship may be extremely stressed. Such reasons include fond memories, gratitude, feelings of responsibility and guilt, and fear of social condemnation (Lezak, 1978).

It should be noted here that the criticisms made above pertain to the research methods used and do not imply that the difficulties found do

not exist. The fact remains, however, that for these difficulties to be adequately identified the research techniques used need to be significantly improved.

A number of authors have indicated that the partners of people with head injury have special needs that are peculiar to this type of relationship (as opposed to the parent-child relationship). Zeigler (1987) suggests a number of areas that pose difficulties for partners. These include the fact that the uninjured spouse must often take singular responsibility for a variety of tasks that may not have been within their domain before the injury occurred. These additional demands may be compounded by the unique care needs of their partner. The healthy spouse may experience feelings of entrapment because they cannot divorce or separate with dignity or good conscience (Lezak 1978). Thoughts of leaving may result in guilt, possibly contributed to by social attitudes and the realisation that there is no-one else to care for their injured partner.

Lezak (1978) tells us that healthy partners essentially live in social limbo because they may not have a partner to participate in social activities with, but are not free to find another. They cannot mourn decently. They may have essentially lost the person with whom they had a relationship, but parts of them are still there. Society does not recognise this sort of grief or provide the necessary support or sanctions for mourning this kind of loss. The uninjured partners' sexual and affectional needs may not be met as many people with head injury have a lowered capacity for empathy and interpersonal sensitivity.

A number of reasons for the greater burden experienced by partners compared to parents of people with head injury have been suggested. Panting and Merry (1974) suggest that, where a person with head injury is living with their parents, and both parents are alive or together, two people would be able to support each other in dealing with any problems and could share the burden between them. They also suggest

that the average age of people with head injury who are living with their parents is less than that of people living with their partners. Because recovery from head injury is usually more complete in the young, parents may experience less difficulties, or difficulties over a shorter time, than partners. Finally, Panting and Merry suggest that parents may be better able to deal with the outbursts of rage that are common after head injury because of the natural exercise of discipline or authority that occurs within the parent-child relationship.

A final explanation for the greater difficulties experienced by partners as a result of head injury is that partners may experience a greater degree of role change with respect to the head injured person than parents do. Thomsen (1978) states that role change in marriage is very common and is a great danger to family life. Rosenbaum and Najenson (1976) state that the head injured men in their study often became very childlike in their behaviour, and that while the spouses of these men found this tendency to be extremely aversive, it was hypothesised that the parents of the injured men may find this to be gratifying. This may be due to the role changes that are necessary in accommodating this sort of change. While the partners of these men may have had to become, in some ways, parents to their husbands, the men's parents were actually resuming a familiar role that may have been, to a degree, relinquished.

#### **Research Outcomes Indicating Greater Levels of Stress In Parental Relationships**

The only study reviewed here to have found that parents experience more difficulty than partners is that of Oddy et al (1978a). Essentially, this study found that there was no significant difference between parents and partners of people with head injury in terms of their scores on the Wakefield Depression Scale, but the tendency was for parents to have higher scores, thus indicating a greater degree of depression. It is not possible, however, to make inferences from this

result, primarily because of the small number of spouses who took part in this research, and because of the non-significance of the result. When these factors are taken into account and this result is viewed in the context of the other research done in this area, it does not seem very probable that the thesis of parents experiencing greater stress than partners is very viable.

### **Qualitative Differences in Stress**

A number of studies have found that parents and partners do not experience significantly different amounts of burden but do show different patterns of stress. Livingston et al (1985a & b) found that, within the severely injured group, there was no significant difference between wives and mothers in terms of psychiatric symptomatology, probability of psychiatric disturbance, or global social adjustment (1985a).

Some differences were however found in the patterns of psychiatric stress and experienced burden. At the three month follow-up, comparisons were made between the wives and mothers of severely and mildly injured men. It was found that wives of severely injured men (compared to the wives of mildly injured men) showed significantly higher GHQ and Leeds Anxiety scores and were more likely to show a clinically significant psychiatric disturbance according to their GHQ measures. Mothers of severely injured men, however, only showed significantly higher Leeds Anxiety scores. There were no other significant differences between them and the mothers of mildly injured men (Livingston et al, 1985a).

In terms of the perceived burden ratings, no statistically significant differences were found, but there were different patterns in the changes in these ratings over time between mothers and wives (Livingston et al, 1985b). While mothers were found to show a modest improvement in burden, the burden perceived by the wives in this study

was found to increase until the six month follow-up when it remained the same until twelve months after the accident (Livingston et al, 1985b).

This brings into question the efficacy of large-N statistics with their tendency to smother results that may have clinical or research significance, if they do not reach significance statistically.

Several other differences in the patterns of needs between parents and partners of people with head injury have been touched upon by other authors. Weddell et al (1980) found in their two-year study of forty four severely head injured people that the parents of a number of them were nearing retirement age and thus found the demands of this situation very difficult. One of the acute worries of this group concerned the eventual fate of their son/daughter, an issue that is not likely to be of such acute significance to the partner of a person with head injury.

Both Lezak (1978) and Zeigler (1987) put forward cogent arguments for different patterns of needs between partners and other relatives of people with head injuries. Rosenbaum and Najenson (1976) identified another difference between partners and parents, namely the presence of tension between wives and their parents in-law, which stemmed from the over-protective attitude of the head injured person's parents. This would not be a source of conflict where the head injured person is single and returns to their parents' home.

Overall, there are a range of research findings examining the relevance of the type of family relationship to the stress experienced by family members as a result of head injury. The general consensus seems to be that marital relationships are more vulnerable than parental relationships, although the reasons for this are unclear, and are likely to be complex.

### Summary

In summary, this chapter has been concerned with various aspects of head injury and its consequences for the families of people with head injuries.

It is obvious that head injury is becoming increasingly prevalent. It is a disability recently recognised through improvements in medical technology.

Recovery from head injury is usually incomplete and occupies two main phases, the initial or primary recovery of physical and mental functions, and secondary recovery, which involves gradual adaptation to any residual disabilities as well as familial and social changes.

The disabilities that may result from head injury are many and varied. A number of physical, cognitive and behavioural/emotional disabilities and changes have been identified.

The families of people with head injury experience a great deal of stress, primarily as a result of the cognitive and personality changes sustained by the head injured person. The stress and burden involved in having a head injured partner or relative can affect the physical and psychological well-being of family members.

In general, it is thought to be the marital relationship that is the most vulnerable to the stress that results from head injury, although the reasons for this are unclear. This is a complex issue that involves many factors.

Because of the important role played by the family in the continued recovery and ongoing functioning of people with head injury, an understanding of the difficulties faced by families, and the corresponding provision of support is essential.

## CHAPTER THREE - STRESS, APPRAISAL AND COPING

### Introduction

This chapter contains an overview of the three main conceptualisations of stress. Of these three, Lazarus' Transactional approach has the most theoretical relevance to the present study because it takes into account the fact that many different things may be perceived as stressful by people in this position. It does not assume that the same things are stressful for all people. It also measures the everyday, practical things whose effects can mount up and contribute to perceived stress.

The initial theoretical overview is followed by a summary of Lazarus' theory. The main components of Lazarus' theory, namely Stress, Cognitive Appraisal and Coping, are then examined in more detail. It should be noted here that because the components of Lazarus' theory are very interrelated it is difficult to separate them and, in fact, to do so does not make sense conceptually. Thus, some repetition between the sections concerned with each component is inevitable, but will be minimised.

### Theories of Stress

The concept of stress, although inconsistently defined, has attracted a great deal of scientific attention, resulting in a vast proliferation of both theories and literature (Cameron & Meichenbaum, 1982). It can be said that every formulation of stress contains a grain of truth, because all demands on our adaptability evoke the stress phenomenon (Selye, 1982), regardless of how it is defined. The definition given to stress depends largely on the model of stress being used. Three main models of stress have been identified, each having their own operational definition of stress and measurement methods for quantification (Derogatis, 1982). These three models may be labelled

in terms of the ways in which they define stress - the Stimulus Model, the Response Model, and the Transactional Model, to which Lazarus' theory belongs. Each of these will be briefly reviewed in turn.

### **Stress as a Stimulus**

In this model, stress is conceptualised as a potential that exists within the stimulus properties of a person's environment (Derogatis, 1982). Thus, those aspects of the environment that are defined as demanding are said to impose stress on the individual. The major, and most consistent approach to measuring stress in this model is the Life Events method. This approach involves identifying life events that involve change, and ascribing scaled weights to these events according to the degree of change, and therefore stress, that they engender.

The basic hypothesis of this approach, therefore, is that the incidence of change is equated with stress. Greater amounts of change in the form of weighted life events are associated with higher incidences of various forms of symptomatology, for example, physical illness.

There are a number of conceptual and methodological difficulties with this approach. Firstly, and most relevant to the present study, is the fact that this approach does not take into account the individual's subjective interpretation of the event. This idea, that the desirability or undesirability of the change is irrelevant has been challenged by a number of authors. For example, Vinokur and Selzer (1975, cited in Derogatis, 1982) found that stress related measures of affect and symptoms were selectively related to negative, rather than positive, life events. Byrne and White (1980, cited in Derogatis, 1982) found that with patients suffering from myocardial infarctions, life events measures have little discriminative power when they do not take into account the meanings that the patients ascribe to the events.

Secondly is the issue of the differential weighting of the events. It

has been suggested that this may be predictively irrelevant. This criticism makes sense in that the weights given effectively impose meanings on the events in terms of the severity of the amount of change incurred. This does not take into account what the events mean to the individual whose stress is being assessed. Finally, life events measures have been criticised for representing life stress as unidimensional, in that life stress is often reduced to a single, overall score. This score could easily obscure any distinct domains or areas of life stress that may contribute to the whole.

### **Stress as a Response**

The primary focus of this model is on the responses of the individual. These are thought to be primary evidence of the existence of stress. The presence of stress is defined by the response of the individual to environmental events. Such responses may be basic physiological responses, or may be more complex psychological responses, such as the presence of negative affect. Such patterns of response are thought to be precursors to or instrumental in the development of dysfunction (Derogatis, 1982).

The origin of response-based theories is generally thought to be Selye's General Adaptation Syndrome (GAS) (1936, cited in Selye, 1982). The GAS consists of three stages - firstly the Alarm Reaction, which is followed by the Stage of Resistance, and finally, Exhaustion. This general syndrome is said to indicate the presence of stress which is defined as "the nonspecific ... result of any demand upon the body, be the effect mental or somatic" (Selye, 1982, p 7). This same reaction may occur in response to many different stimuli.

There are also several problems with the Response Model. The most important of these is concerned with the generalisability ascribed to Selye's GAS. As stated above, the GAS is said to occur in response to any stimulus. The question must, therefore, be asked. Why is there

no differentiation between responses to different stimuli? The second main criticism of the response approach is the fact that, like the Stimulus model, the Response Model makes no allowance for individual interpretations of stimuli. According to Selye's theory vastly different events produce the same basic reactions in everybody. Within the model no importance is given to the reasons why people react in certain ways to stimuli that indicate that they are experiencing stress.

### Stress as a Transaction

The third main approach to stress is the Transactional Model. In this approach stress is not seen as either an environmental stimulus or as a response to a stimulus but is defined as the relationship between the person and the environment. "Stress does not reside in any one variable, but is a product of many interacting person and environmental antecedents, mediating processes, ... and short-term and long-term outcomes, each capable of influencing the other" (Gruen, Folkman & Lazarus, 1988, p 744). In more concrete terms the person and their actions, perceptions and cognitions affect the environment and the environment influences the actions of the person.

In this, a bi-directional dynamic system of feedback loops is conceptualised in which the characteristics of the organism act as mediators between environmental characteristics and the responses that they evoke (Derogatis, 1982). The distinction must be made here between this model and the interactional model in which unidirectional causality is inferred between the person and their environment. By definition, therefore, transactional theories are concerned with two things. Firstly, stress is seen as a process rather than a static variable. This comes from the dynamic focus which sees stress as ever changing due to the feedback loop operating between the person and their environment. Secondly, the role of cognition becomes important because of the mediating role attributed to the cognitive and

perceptual characteristics of the person. From this it can be seen that an environmental event or stimulus can only be defined as a stressor by the person perceiving it. Thus, what may be perceived as stressful by one person may not necessarily be perceived in the same way by another.

Several difficulties with the Transactional Model of stress have been noted. One problem is that identified by Derogatis (1982), namely the difficulty in adequately measuring stress as it is defined by this model. The transactional definition of stress "carries the implication that accurate measurement of the stimulus field, the response spectrum, or stable mediating traits of the individual would be insufficient to capture the essence of the phenomenon since the dynamic reciprocal relationship among them would constantly alter component values" (Derogatis, 1982, p 273).

A second issue is that of circularity. It could be said that the Transactional Model, for example that used by Lazarus and his colleagues, uses a circular argument and thus explains nothing. To use Lazarus's approach as an example, the person's available coping mechanisms and resources are one group of variables that influence whether any encounter is appraised as being stressful. Thus coping abilities act as a causal agent. However, coping strategies are also an outcome of the appraisal process which determines whether the use of such strategies is actually necessary. Thus, coping is also an outcome. From this it can be seen that it is conceptually difficult to determine what is actually being measured.

"In the final analysis, the conclusions one reaches concerning the adequacy of (any) approach to stress measurement are defined in large part by one's measurement requirements" (Derogatis, 1982, p 275 - 276). The Stimulus Model, and more specifically, the Life Events approach, is unsuitable for the present study primarily because it is already obvious that the participants in the study have experienced a traumatic life event in the form of their partner/son/daughter becoming head

injured. The consequences of this and subsequent life changes, and their meaning for the participants, is what is considered important here, and thus, measuring life change would be superfluous.

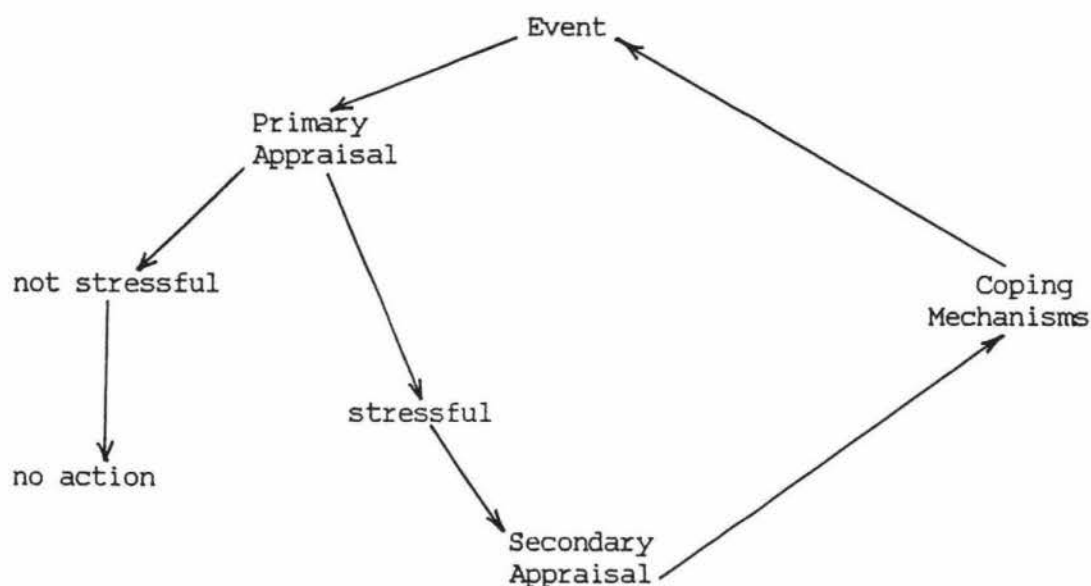
The Response Model also makes little sense in the present context as it does not take into account the events preceding the responses and their subjective meanings. Response-based measures also tend to measure what the person 'usually does', or 'would do' in certain situations. Such measures are not as accurate as those that address what a person actually did in a given situation, and the meaning that the situation had for them. The Transactional Model has several flaws also, as mentioned previously. However, it is obvious that neither of the linear models of stress are able to adequately explain stress as a phenomenon with consequent human reactions to it. The Transactional Model provides the most appropriate conceptualisation for use in the present study.

### Lazarus' Theory of Stress

The theory of stress and coping put forward by Lazarus and his colleagues (eg Lazarus, 1966; Kanner, Coyne, Schaefer & Lazarus, 1981; Lazarus & Folkman, 1984) has been described as a "Cognitive-Phenomenological Theory" (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p 992). This approach is examined in more depth in this section. Firstly a brief overview of what occurs in a stressful situation, as conceptualised by Lazarus, will be given. The terms used in this overview will then be examined in more depth.

### **Overview of Lazarus' Theory**

According to Lazarus' theory, a number of things occur during a stressful encounter, which are summarised in Figure 2.



**Figure 2:** Diagrammatic summary of Lazarus' theory of Stress, Appraisal and Coping.

Through Primary Appraisal, the individual evaluates the situation they are in as being either stressful or not. According to this theory, "the extent to which a harmful or potentially harmful encounter between the person and the environment is stressful depends on the meaning or significance of that encounter, which is in turn based on the personal agendas and coping resources the person brings to it" (Gruen et al, 1988, p 744). Should the situation be judged to be stressful, Secondary Appraisal is used to evaluate one's coping resources with regard to the particular circumstances. These two forms of Cognitive Appraisal are important mediators of the individual's responses to stress. "Primary and secondary appraisals converge to determine whether the person-environment interaction is regarded as significant for well-being" (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p 993). However, it should be noted that they do not necessarily occur in the temporal order indicated. With the appraisal of a situation as being stressful, coping mechanisms are set in place dependent on the results of the Secondary Appraisals. As the Coping strategies take effect and the situation changes, or does not change, ongoing Primary and Secondary Appraisals are made, prompting the use

of different coping strategies. This feedback process continues until the situation is no longer appraised as being stressful.

A number of terms have been introduced here. These will now be examined more thoroughly with regard to the theory that lies behind them and in terms of applied research. Although Lazarus' theory views stress appraisal and coping as interdependent (Lazarus & DeLongis, 1983), these concepts will be examined separately in order to clarify the functions of each one.

## **Stress**

The underlying premise of Lazarus and his colleagues' approach to stress is that stress is what it is perceived to be. Thus, a stressor cannot exist on its own. It needs to be perceived as a stressor. This is the basis of the definition of stress given by Lazarus and Folkman (1984, p 19): "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being".

This is a relational definition of stress. Lazarus' theory states that it is not possible to adequately define stress in an objective manner. It is necessary to take into account the characteristics of both the person and the environmental event. This is illustrated by the fact that, while extreme environmental conditions generally result in stress for nearly everyone, the milder the stressor becomes the more variability there is in people's reactions to it (Lazarus & Folkman, 1984). Thus, stress does not lie in the stimulus or the reaction to it but is a product of the relationship between the person and their environment. This definition of stress is parallel to the modern concept of illness. Illness is now not seen as being caused solely by an external agent. The occurrence of illness depends also on the organism's susceptibility to that agent.

## Cognitive Appraisal

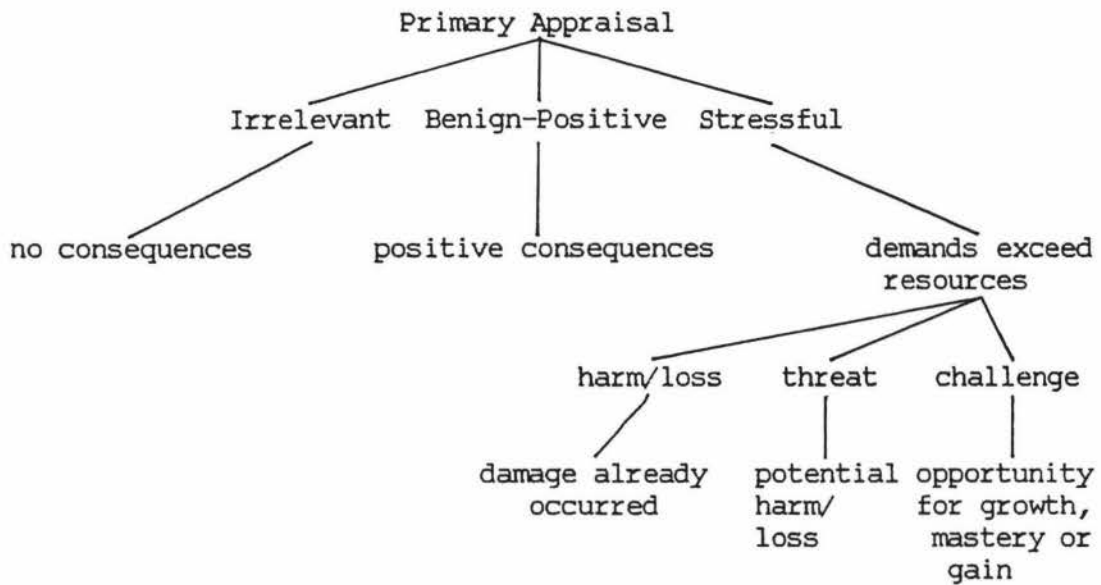
Cognitive Appraisal is "a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and if so, in what way" (Folkman et al, 1986, p 992). Cognitive Appraisal is an important mediator of the effects of the appraised stressor on the person's responses to it. A mediator and its' functions have been defined as "a variable that transmits, in some form, the causal influence of one variable (an antecedent) to another (a consequence)" (James & Brett, 1984, cited in Zika & Chamberlain, 1987, p 155). Thus, Cognitive Appraisal acts to transmit the effects of the appraised stressor and thus help to determine their reactions to the stressor.

This evaluation of the situation directly influences the coping behaviours that follow the appraisal. This relationship has been empirically demonstrated by Folkman et al (1986), who showed that Cognitive Appraisal (both primary and secondary) contributed to the variability in the coping strategies used by their subjects in the face of stressful encounters. Cognitive Appraisal was also found to be related to the outcomes of stressful encounters.

There are two main types of Cognitive Appraisal. These are Primary Appraisal and Secondary Appraisal. Both are dealt with separately in the following two sections.

### Primary Appraisal

Primary Appraisal is the evaluation of a situation in terms of whether the person has anything at stake in the encounter. Put another way, primary appraisal involves the judgement of a situation in terms of the possible effects it may have on the person. This is summarised in Figure 3.



**Figure 3: Summary of primary appraisals and their consequences.**

As shown above, there are three major types of judgement that can be made: the situation may be appraised as being either irrelevant, benign-positive, or stressful.

If a transaction is appraised to be irrelevant, it is judged to have no significance, positive or negative, for the person's well-being, and thus, does not require the person to activate any coping strategies (Folkman, 1984). When a transaction is appraised as being benign-positive, it is judged to be relevant, but not to tax or exceed the person's resources. This appraisal signals only positive consequences, and does not require the mobilisation of coping strategies (Lazarus & Launier, 1978).

If an encounter is appraised as being stressful, the demands of the situation are judged to tax or exceed the person's resources, and negative consequences are foreseen. There are three kinds of stressful appraisal - harm/loss, threat, and challenge, and each is characterised by specific accompanying emotions (Folkman, 1984). The harm/loss appraisal is made when an encounter involves injury or damage that has

already occurred, and is characterised by negative emotions such as anger, fear or resentment. Like benefit appraisals, harm/loss appraisals are primarily concerned with what has already occurred (Folkman & Lazarus, 1985).

A threat appraisal indicates a potential harm/loss, such as upcoming examinations, and is also characterised by negative emotions. A challenge appraisal indicates that the person perceives an opportunity for growth, mastery or gain, for example an impending sports match. Such appraisals are generally characterised by more pleasurable emotions, such as excitement or eagerness (Folkman, 1984), and, along with threat appraisals, are anticipatory in nature (Folkman & Lazarus, 1985).

The three types of stress appraisals described above are not mutually exclusive and may all occur with respect to the same event. This was demonstrated by Folkman and Lazarus (1985) in their study of appraisal, emotion and coping before and after a college examination. This piece of research showed that the emotions associated with threat, challenge, harm and benefit appraisals were present at different times in relation to this stressful transaction.

Primary appraisals are influenced by a number of factors. These have been grouped into two categories - person factors and situation factors. Person factors that affect primary appraisals include the person's beliefs and commitments. "Any encounter that involves a strongly held commitment will be evaluated as significant with respect to well-being to the extent that the expected outcome harms or threatens that commitment" (Folkman, 1984, p 841).

The situation factors that are said to influence primary appraisals vary greatly and are basically different aspects of the event itself. These factors include the nature of the harm or threat, the novelty or familiarity of the encounter, the probability of the event occurring, the clarity or ambiguity of the outcome of the event, and when the

event will occur (Folkman, 1984).

### Secondary Appraisal

Whereas primary appraisal involves the evaluation of the situation in which the person finds themselves, secondary appraisal is concerned with the evaluation of coping resources and options. The term 'secondary' does not indicate that secondary appraisal follows primary appraisal or is of less importance (Lazarus & Launier, 1978). The temporal order of these two forms of appraisal is not fixed. Secondary appraisals may be made and memorised before any stressful primary appraisals are made. For example, we may take note of how to escape from a theatre or prepare for exams well before such threats occur and this knowledge can then be used once the danger is actually perceived (Lazarus & Launier, 1978). Like Primary Appraisal, Secondary appraisal has direct influence over the coping strategies used. This was demonstrated by Folkman et al (1986), in their research concerned with peoples' perceived ability to change a situation. As hypothesised, it was found that when the situation was appraised as being changeable (ie secondary appraisal indicated that existing coping mechanisms were adequate to deal with the situation), the subjects used problem-focussed coping strategies with the intent of making changes in the actual situation. On the other hand, when the situation was appraised as being unchangeable, emotion-focussed coping strategies were used with the aim of coping with the situation without changing it. These two forms of coping will be discussed in greater depth in the next section.

The outcome of secondary appraisal has an effect on both the person's primary appraisal of the situation (Mason, 1987), and the coping processes they use. That is, if the person's coping resources are appraised as being adequate to deal with the stressful situation, then the degree of threat is lessened. Alternatively, an event that is initially appraised as being nonthreatening may become a threat if the

person's coping resources are found to be inadequate for dealing with the demands of the situation (Folkman & Lazarus, 1985). On the other hand, if the situation is appraised as being one that the person can do something about, then the primary appraisal may change from that of threat to one of challenge. This illustrates the continual feedback that is the basis of Lazarus' theory of stress and coping.

The utility of the concept of secondary appraisal has been questioned by Dobson and Neufeld (1979), who found in their study that the major predictor for the anticipated degree of stress in their subjects was the subjects' primary appraisal of the situation. They stated that "while it appears that both types of appraisal do in fact occur ... it does not seem necessary to detail both aspects before being able to predict stress responses for males in an ego-threatening situation" (Dobson & Neufeld, 1979, p 283).

## Coping

Coping is defined in this context as the continually changing cognitive and behavioural efforts to manage, that is, master, reduce or tolerate, the internal and/or external demands created by a transaction that is appraised as taxing or exceeding the person's resources (Folkman, 1984; Folkman et al, 1986).

## Key Features of Lazarus' Theory of Coping

There are three key features of this theory of coping that both define and set it apart from other approaches, namely its process orientation, its contextual approach, and the lack of assumptions made regarding the outcome of coping strategies.

### *1. Process Orientation of Lazarus' Theory*

Because of the process orientation of Lazarus' theory, the focus is on what a person actually thinks and does in a specific encounter and how this changes as that encounter unfolds, or over different encounters (Folkman et al, 1986). This feature has several important components. They include the concern with what is actually done and the focus on change.

The object of study under this approach to coping is what the person actually did in a specific transaction. The focus on what actually occurs allows specific coping strategies to be linked to specific demands (Mason, 1987). This enhances the development of a comprehensive theory of stress and coping. This differs from trait approaches to coping which focus on what the person usually does. There are two problems with the trait approach that are relevant here. Firstly, the recollection of what is usually done will be less accurate than the recollection of what was done in response to a single event. There are two reasons for this. Inherent in this method is the 'averaging' of many experiences over time. There is a high probability that a number of experiences and reactions will not be included in the final indication of the coping methods used. Also, recollection under the trait approach generally takes into account a longer time span. The difficulties with the accuracy of information recalled over a long period of time due to memory failures are well-documented (Kidder & Judd, 1986).

A second problem with trait approaches is that they emphasise stability rather than change (Folkman et al, 1986). This view ignores empirical evidence that suggests that coping is multidimensional and characterised by change (Mason, 1987). The emphasis on change in Lazarus' approach is an essential part of this theory - "the essence of stress, coping and adaptation is change" (Folkman & Lazarus, 1985), and is the foundation of the process orientation, and thus is the key to Lazarus' theory. That coping strategies change as an encounter unfolds has been demonstrated by Folkman and Lazarus (1985) in their

study of appraisal and coping in college students referred to earlier. As with appraisals, the coping strategies used changed as the situation unfolded, and its demands changed. This is the very nature of process.

## *2. Contextual Focus of Lazarus' Theory*

The second key feature of Lazarus' theory of coping is its contextual view. This approach states that specific coping efforts are shaped by specific person and environment variables in the context of a specific encounter (Folkman et al, 1986). This specificity is a hallmark of Lazarus' approach, and once again allows for the development of a comprehensive theory of stress and coping. Lazarus' approach can be seen to differ from both state and trait approaches here, in that both person and environment factors have influence, rather than one or the other being predominant.

## *3. Assumptions About Outcomes in Lazarus' Theory*

The third key feature is the fact that no assumptions are made about the outcome when coping is defined (Folkman et al, 1986). Thus, coping is not defined in terms of success/failure, or good/bad strategies. The primary focus is what the person actually did at the time. This feature differentiates Lazarus' theory from other approaches. For example, psychodynamic theories consider certain intrapsychic defenses such as denial, to be poorer than others, such as suppression. Lazarus' approach also differs from many popular conceptions of coping, in which 'coping' implies succeeding, as opposed to 'not coping', which refers to failure (Folkman, 1984).

This third feature is important in terms of the measurement of coping. Because the definition of coping, and thus its measurement does not include the outcome of the coping strategies, there is no confounding between coping efforts and outcomes. This is extremely important in terms of the usefulness of the concept of coping in the prediction of outcome, which would be meaningless if the two were confounded

(Folkman, 1984).

### Types of Coping

Coping is seen as having two major forms, namely, emotion-focused coping and problem-focused coping, both of which serve a particular function. These two forms of coping are outlined below. This is followed by a description of their interrelationship.

#### *Emotion-Focussed Coping*

Emotion-focussed coping is used to control the emotions that result from a stressful encounter that might otherwise interfere with problem-focussed coping strategies. Thus, one of its major functions is to change the way in which the encounter is construed or attended to. This alters the person's emotional reactions to it directly (Lazarus & DeLongis, 1983), and enhances their feelings of control over their distress (Folkman, 1984). This form of coping is referred to variously as defensive reappraisal (Lazarus, 1966), or simply reappraisal (Lazarus & Launier, 1978, cited in Folkman, 1984).

A variety of emotion-focussed coping strategies have been identified. These include distancing, escape-avoidance, self-control, accepting responsibility, and positive reappraisal (Folkman et al, 1986). Seeking social support has also been identified as containing both problem- and emotion-focussed components. Other researchers have found different but similar forms of coping. For example, Vitaliano, Russo, Carr, Maiuro and Becker (1985) generated the emotion-focussed scales of blaming oneself, wishful thinking, and avoidance, as well as problem-focussed and seeking social support scales.

#### *Problem-Focussed Coping*

Problem-focussed coping is used to control or change the person-environment relationship that is causing distress (Folkman, 1984).

Problem-focussed coping strategies can include such things as problem solving, decision making and direct action (Folkman, 1984), interpersonal confrontation strategies (eg expressing anger towards the person who caused the problem) and intrapersonal cognitive strategies (eg telling oneself things that make you feel better) (Folkman et al, 1987). Within their function of controlling the troubled person-environment relationship, problem solving strategies can be directed at either the environment, in the form of taking action against the external source of the stressful transaction, or at oneself, by changing something about oneself that ultimately changes the relationship between the person and their environment. Such actions will alter the primary and secondary appraisals that are continually made, thereby altering the emotions associated with the situation.

*The Interrelationship Between Emotion- and Problem-Focussed Coping*

The effectiveness of problem-focussed techniques used depends, to an extent, on the effectiveness of emotion-focussed coping strategies which serve to regulate those emotions that could interfere with the cognitive strategies necessary for problem-focussed coping (Folkman, 1984).

It is for this reason that most encounters are dealt with by using combinations of both types of coping. This has been demonstrated in a number of studies concerned with this area. Folkman and Lazarus (1980, cited in Folkman & Lazarus, 1985) found that in their middle-aged community sample, 98% of the more than 1300 stressful encounters reported over a year were dealt with by using both forms of coping. Folkman and Lazarus (1985) had similar results.

Any thought or action can, in fact, have multiple coping functions, and it is not easy to distinguish between problem- and emotion-focussed coping in functional terms. Feelings may actually be regulated by solving problems and vice versa. For example, a student taking a sedative to control the distress that would normally interfere with

their examination performance is problem solving by attempting to manage their feelings. Alternatively, a student who prepared carefully for an examination by studying so that they could feel that they were mastering the threat that the examination posed, would be managing the distress of doing badly through problem-focussed coping (Lazarus & Folkman, 1984). Thus, the focus of a coping strategy must be defined by its functional characteristics rather than pigeon-holing it according to its initial appearance.

The extent to which a person uses Problem- and Emotion-focussed coping strategies depends on their primary appraisal of what is at stake in the encounter and their secondary appraisal of what can be done about the situation (Folkman et al, 1987). In the research conducted by Folkman et al (1986), various coping strategies were associated with certain primary appraisals. For example, when there was appraised to be a high degree of threat to self-esteem, subjects used more confrontive and self-control methods of coping, accepted more responsibility, used more escape-avoidance and sought less social support than when this threat was low. Folkman and Lazarus (1980, cited in Folkman & Lazarus, 1985) found that problem-focussed coping strategies were more predominant in encounters that were appraised as changeable, whereas emotion-focussed coping was used more in situations appraised as being unchangeable. This pattern was also found in subsequent research (eg Folkman et al, 1986).

The ways in which a person copes with a stressful encounter helps to determine their emotional response to the stressful situation (Lazarus & DeLongis, 1983). Many coping strategies may actually contain an appraisal component, in that they serve to shape the meaning of a given situation, and thus control distress (Folkman, 1984). Therefore it is useful to consider control-related cognitive processes that are involved in appraisal and coping as having separate but related functions (Folkman, 1984).

### Summary

The focus of this chapter has been stress theory, and has included an overview of three major models of stress. Indications have been given regarding the inappropriateness of the Stimulus and Response models of stress. Arguments for the utility of the Transactional model have also been put forward.

The major part of this chapter has been devoted to detailed coverage of Lazarus' theory of stress and coping, which includes explanations of key concepts of this approach, and an overview of relevant research.

## CHAPTER 4 - HYPOTHESES AND SYNTHESIS

### Introduction

This chapter aims to synthesise the empirical and theoretical bases for the present study, integrating the facts on head injury, and Lazarus' theory of stress. The first part of this chapter outlines the hypotheses of the present study. The second section briefly indicates the relevance of Lazarus' theory to the area of head injury research.

### Hypotheses

Hypotheses were proposed for the three main research areas of the present study and two of the three other areas that were examined. The hypotheses are numbered from 1 for each construct area.

### Stress

Previous research has shown that relatives of people with head injuries, including parents and partners, experience significant stress levels. The results of the present study were expected to be congruent with this. It was generally hypothesised that differences in perceived stress between parents and partners would be found. Two specific hypotheses were proposed with regard to Stress. These are:

1. That Partners will be found to experience quantitatively more stress than parents.

This is based on a number of studies concerned with the effects of head injury on the family. These have suggested that partners of people with head injuries experience more difficulties than parents (eg Thomsen, 1978; Panting & Merry, 1974; Blyth, 1981; Lezak, 1978; Zeigler, 1987).

2. That the two groups will show qualitative differences in perceived stress.

This also comes from head injury research. Previous findings state that patterns of difficulty stemming from effects of head injury on both the injured person and the rest of the family differ between parents and partners (eg Livingston et al, 1985a & b; Rosenbaum & Najenson, 1976; Weddell et al, 1980; Lezak, 1978; Zeigler, 1987). Some stress research suggests that the different roles played by people (in terms of gender, age, and relationships to others, for example) can influence the stresses they perceive as being relevant to them. Such findings are supported by research by Chamberlain and Zika (1990), Kanner et al (1981), and Folkman et al (1987).

### **Role Changes**

Several authors have indicated that relatives of people with head injuries experience a degree of role change as a results of the effects of the head injury. It was generally hypothesised that there would be differences between the two groups of participants in the present study in terms of the Role Changes they experience. Specifically the hypotheses of the present study state that:

1. Partners will experience quantitatively more Role Change than Parents.
2. There will be qualitative differences in Role Change experienced by the two groups.
3. A positive correlation will be found between Stress and Role Change.

The first and second Role Change hypotheses are based on the suggestion made by Thomsen (1978) that role changes experienced by partners of head injured people are great, and can have a large impact on the

family. Rosenbaum and Najenson (1976) also suggest that there may be a difference in the role changes experienced by parents and partners. This suggestion is made with reference to the childish behaviour shown by many of the head injured men in their study. This was abhorrent to their partners, but it was suggested that their parents may have found it gratifying.

The essence of this hypothesis is that it will be more difficult for a person to parent their partner than it will be for a parent to return to a former role with regard to their head injured son/daughter.

### **Social Support**

A number of authors have shown social support to be important in the processes of dealing with stress (eg Kaplan, Cassel & Gore, 1977; Lefcourt, 1985). People generally have a number of sources of social support, and receive different types of support. In the present study it was generally expected that Parents and Partners would differ in terms of the social support they received. The specific hypotheses related to this state:

1. That Parents would receive quantitatively more Social Support than Partners.
2. That Parents Social Support would differ qualitatively from Partners Social Support in terms of the sources and types of support received.
3. That there would be a negative correlation between Stress and all indices of Social Support except Need for Social Support, which would be positively correlated.

One of the major differences in the sources of social support was expected to be, in the case of parents of people with head injury, the fact that there may be two parents who can share the burden and help

each other with problems involved in living with a head injured son/daughter. This is based on the concepts promoted by Panting and Merry (1974). It is not expected that partners will receive this sort of support from their head injured partner. This factor was expected to contribute to both quantitative and qualitative differences between the two groups.

### **Other Research Areas**

Three other areas were explored within the present study, although they do not form the main focus of the research. These areas were: Health Problems, Coping and Information.

#### Health Problems

Several authors have noted the incidence of elevated health problems in relatives of people with head injury. Congruent with the hypotheses concerning stress it was expected that:

1. Partners would experience quantitatively more Health Problems than Parents.
2. There would be a positive correlation between Stress and Health Problems.

#### Coping

The coping strategies of both groups were examined to test the following hypotheses:

1. That the Parents and Partners groups combined as a whole would use certain coping strategies more than others.

2. That Parents would use more Problem-focussed coping strategies than Partners, and Partners would use more Emotion-focussed strategies than Parents.

### Information

Many studies concerned with the families of people with head injury have found that family members are often dissatisfied with the information they were given at the time of injury (eg Thomsen, 1978). The aim of this section of the present study was to determine whether participants felt that they were told enough about their partner/son/daughter's current condition, possible outcomes and head injury in general. Changes in the participants understanding of the information they received over time were also examined.

### Synthesis - Head Injury and Lazarus' Theory

The aim of this section is to bring together the empirical and theoretical areas within the present study and show why Lazarus' approach to stress was used in the present study and its relevance to the area of head injury research covered here.

Lazarus' theory of stress was used in the present study for a number of related reasons. Because this approach states that stress is what it is perceived to be there is large scope for the recognition of individual differences in perceived stress. This is important in terms of the experiences of relatives of people with head injury. Because the effects of head injury are different for each person, the experiences of members of their families will also differ. Lazarus' approach allows these differences to be recognised as being valid.

Within Lazarus' theory, stress is, in effect 'in the eye of the beholder'. This too has important implications for relatives of people

with head injury. As stated previously one of the sources of difficulty for families is that often there are no outward signs of change in the head injured person. Therefore some of their sources of stress are often not readily apparent. A measure that recognises stress as what is perceived by the relative, rather than what is expected by the researcher or the model being used is therefore very important in validating and recognising the experiences of this group of people.

The dynamic nature of Lazarus' theory which recognises that stress is not a static variable is also important. Changes in the head injured person during their extended recovery time can result in changes in the stress experienced by the relatives of this person. In addition, the family members also change in response to the effects of the head injury. An example of this is the change and family adaptation suggested by Lezak (1986). A measure of stress that allows for this change and adaptation is very important in examining the process of stress in relatives of people with head injury.

## CHAPTER FIVE - METHOD

### Procedure

#### **Ethics Committee**

In accordance with the requirements of Massey University, an application was made to the Massey University Human Ethics Committee for approval of the present study.

The application included a brief literature review and overview of the area of head injury and the theoretical basis of the present study, and the method and instruments to be used. It also gave an indication of potential ethical problems and the ways in which these would be dealt with.

Approval for the present study was granted by the Ethics Committee.

#### **Data-Gathering Process**

The process used for contacting participants and gathering the data used in the present study is presented in Figure 4 (Page 65).

The clients referred to in Figure 4 were past and present clients of the Massey University Psychology Clinic and the Palmerston North branch of the Accident Compensation Corporation. Participants were the parents and partners of these clients.

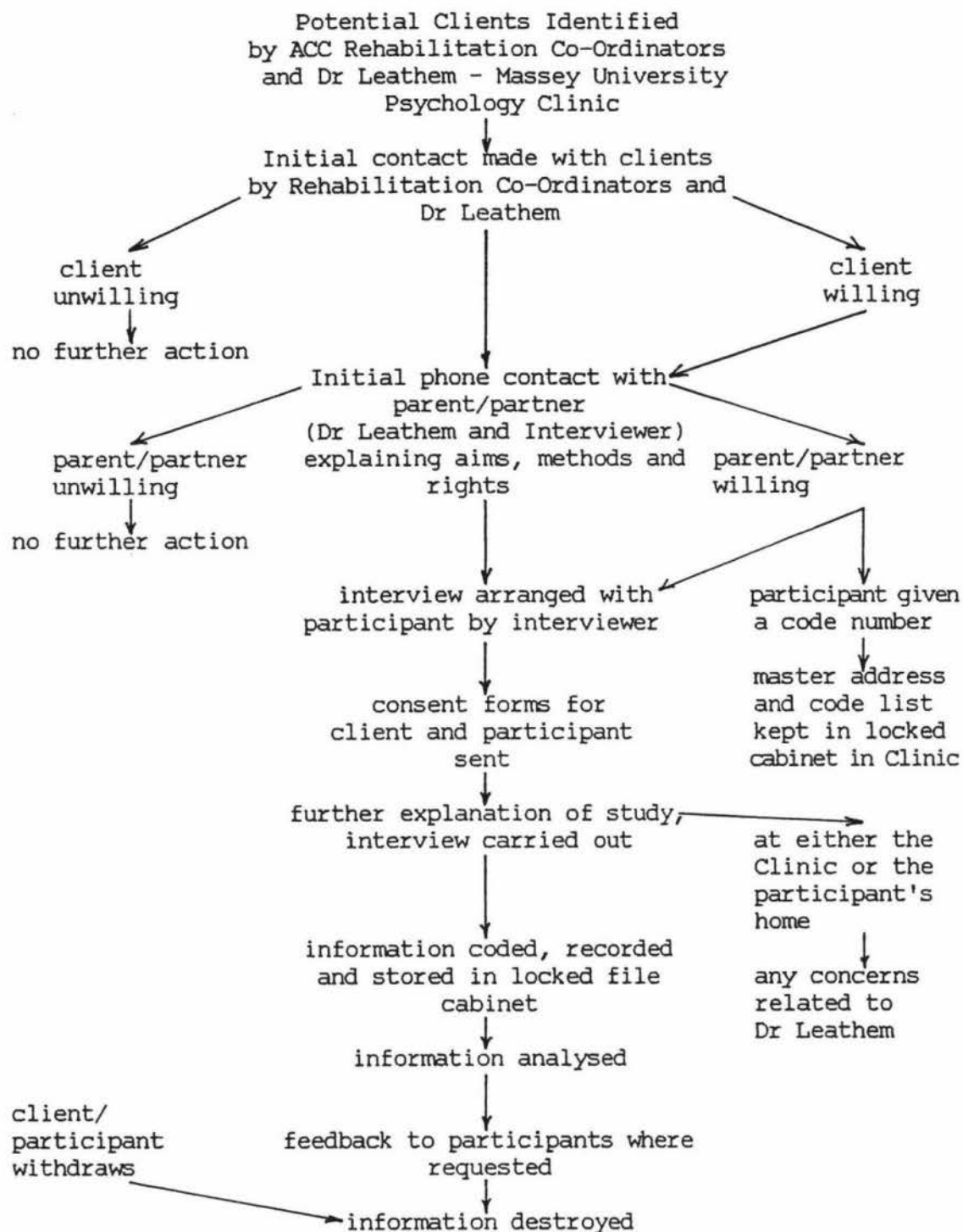
The clients were initially contacted by Dr Leathem, Director of the Psychology Clinic, or their Rehabilitation Co-ordinator. In the event of a positive response from them the participant was then spoken to by the researcher, who explained the nature of the study and where possible arranged an interview time and place. A letter to the client and a letter to the participant, accompanied by a consent form for each

was then posted by the researcher. The researcher then contacted the participant by telephone to arrange an interview time and place if this had not been done. Before the interview started the participant's rights and the researcher's responsibilities were again explained and the opportunity given for any questions to be asked.

It was felt that the clients should be contacted in the first instance to give their permission for their parent or partner to take part in the present study. There were a number of reasons for this, including courtesy to the client and obtaining permission for access to information via the participant. Approaching the client initially also made the process very open and clear. This was felt to be important because people with head injuries often undergo a great deal of assessments and diagnostic testing. It was essential that the clients did not feel that they were being talked about without being included. Thus obtaining their consent from the start minimised any apparent secrecy and therefore stress for the client and consequently for the families concerned.

### Interviews

The interviews took place in either the participant's home, or the Psychology Clinic, as decided by the participant. The study consisted of a single interview. However, if this was not completed in one session, as was the case with several participants, arrangements were made to continue the interview at a later time. The interviews ranged in duration from approximately one hour to approximately four hours.



**Figure 4:** Diagram of the process used in contacting participants and obtaining data.

## Ethical Issues

### Informed Consent

Clients and participants were informed of the nature of the research, what participation would mean for them, their rights as participants and the obligations of the researcher in the initial telephone call and again at the beginning of the interview. Their rights as participants included the right not to answer any questions they did not want to, and to pull out of the research if they did not want to participate further. The obligations of the researcher included maintaining confidentiality and security of any records, providing access to follow-up and providing feedback where this was requested.

### Confidentiality

In order to preserve confidentiality and anonymity throughout the study, each participant was assigned a three-digit code number. All questionnaires were identified only by this code number. There was one master list of all code numbers and corresponding names and addresses. This was kept in a locked file cabinet in the Psychology Clinic Director's office. This was only accessible to the Clinic Director and the researcher. On completion of the research and feedback to participants, the list was destroyed.

### Debriefing

All participants were asked if they wished to receive a summary of the findings of the present study. Those who did received a brief, non-technical summary of the results and conclusions.

### Dealing With Distress Evoked By the Study

The researcher was alert to any signs of distress during the interviews. At the conclusion of each interview, the participant was informed that, should they feel the need, they could call the Clinic and follow-up would be made available.

### Use of Data Once the Present Study Is Completed

The researcher undertook that all the data collected during the interviews would be used only for the purposes of the present research, and would be destroyed on completion of the present study.

### Clients or Participants Wishing to Withdraw From the Study

In the event of a client or participant deciding to withdraw from the present study, or withdraw their consent for the information to be used, the researcher undertook that this would be respected. In one case the client withdrew their permission for the interview data to be used. This information was then destroyed.

## Participants

Participants were 18 parents and 13 partners of people with head injuries. The characteristics of these two groups, and their sons/daughters/partners with head injuries are given in the following tables.

**Table 2:** Age (at time of interview) and gender of participants and sons/daughters/partners with head injuries.

Group		Age		Gender	
		Average	Range	Male	Female
Participants	Parents	48.33	31 - 59	4	14
	Partners	34.31	21 - 62	2	11
	Both Groups	42.45	21 - 62	6	25
Head Injured Person	Son/Daughter	21.44	9 - 30	12	6
	Partner	37.00	24 - 66	11	2
	Both Groups	27.97	9 - 66	23	8

Table 2 shows that the average age of participants in the present study was 42.45 years. Within this, the average age for Parents was 48.33, and for Partners was 34.31. Head injured partners had a higher average age (37.00 years) than sons/daughters (21.44). Most of the participants in the present study were female. Congruent with the literature, most of the people with head injuries in the present study were male.

Of the respondents, both groups are predominantly women. Conversely, of the two groups of people with head injuries, most are men, as is indicated in the literature.

**Table 3:** Cause of injury - sons, daughters and partners of participants.

Cause of Head Injury	Number	
	Sons/Daughters	Partners
Motor Vehicle Accident	15	7
(Car)	(7)	(5)
(Pushbike)	(3)	(1)
(Motorbike)	(3)	(1)
(Pedestrian)	(2)	(-)
Medical Misadventure	1	1
Near Drowning	1	-
Anoxia due to Asthma attack	1	-
Falls	-	2
Assault	-	1
Air Accident	-	1

Table 3 shows that the most common cause of head injury in the above group was motor vehicle accidents. This is congruent with the findings of previous research. Car accidents accounted for the greatest proportion of these for both groups. Medical misadventure occurred in both groups.

**Table 4:** Head injured persons age (years) at the time of injury and time since injury (years).

Group	Age		Time Since Injury	
	Average	Range	Average	Range
Sons/Daughters	17.83	8 - 26	3.60	0.50 - 7.91
Partners	33.92	17 - 65	2.86	0.25 - 8.00
Both Groups	24.58	8 - 65	3.29	0.25 - 8.00

Table 4 shows that the average age of the head injured partners group is almost twice that of the sons/daughters group as could be expected. There is relatively little difference between the two groups in terms of the time since injury.

**Table 5:** Financial and occupational consequences of head injury for the participant group in terms of Socioeconomic Status, Change in Main Earner and Return to Pre-Injury Occupation.

Group	Socioeconomic Status		Change in Main Earner			Return to Pre-Injury Occupation			
	Before	After	Yes	No	N/A	Yes	Yes*	No	N/A
Parents/ Sons/Daughters	3.50	3.66	-	15	3	8	3	5	2
Partners	3.82	4.13	6	6	1	6	3	4	-
Both Groups	3.63	3.82	6	21	4	14	6	9	2

Yes\* = return to work in an altered capacity

Table 5 contains information about change in terms of socioeconomic status, main money earner and occupation of the head injured person following their injury. Socioeconomic status was measured using the Elley-Irving Scale. Within this scale, lower scores indicate higher socioeconomic status. From Table 5 it can be seen that both groups

show a drop in socioeconomic status from before injury to after. The Parents group had a slightly higher status than the Partners group, both before and after injury. For some participants it was not possible to use this measure because either it was not possible to ascertain the status of their occupation, or there was no-one in the household in paid employment.

Table 5 also shows that the Partners group experienced greater change in the main earner after injury than the Parents group. Proportionally, a higher number of Partners than Sons/Daughters did not return to their pre-injury occupation following their head injury. Similar proportions of both groups did return to either their previous occupations or returned to work in a different capacity (eg part-time instead of full-time). These characteristics are congruent with those found in previous research (eg Oddy & Humphrey, 1980).

### Instruments

A number of instruments were used in the present study, to measure stress and associated variables. These, in conjunction with some additional information, are listed below:

#### **The Hassles and Uplifts Scale (DeLongis, Folkman & Lazarus, 1988)**

This scale has been widely used by the Berkeley Stress and Coping Project, and other researchers, to measure stress. As such, it is primarily a research tool, as opposed to a therapeutic measure. The original scale was devised by Kanner et al (1981), and consisted of 117 hassles generated by research staff and participants in an earlier study. Hassles are defined as "the irritating, frustrating and distressing demands that to some degree characterise everyday transactions with the environment" (Kanner et al, 1981, p 3). These hassles fell into the general categories of work, household, family,

friends, the environment, practical considerations, and chance occurrences. The original Uplifts scale was generated in the same manner, and consisted of 135 items, falling into the same categories. Uplifts are defined as positively construed or satisfying experiences (Kanner et al, 1981). Both of these scales had a three point rating scale for the intensity and frequency of each item.

This 'minor events' approach to measuring stress was taken by Lazarus and his colleagues because of the conceptual and methodological difficulties inherent in the Stimulus and Response models that have been outlined in a previous chapter. Lazarus' approach allows researchers to both examine the levels of stress experienced by subjects and to gain some insight into the meaning of these stress levels.

Hassles and uplifts are assumed to operate in such a way that the endorsement of any particular item indicates something of its appraised meaning to the person concerned. Thus, hassles and uplifts are not endorsed simply because they occurred. They are endorsed because they have personal meaning that makes them salient, noticeable, and memorable to the person (Lazarus & Folkman, 1984).

The salience of a hassle or uplift at any particular time is influenced by a number of factors. These are the person and environment factors that affect the person's primary appraisal of the situation. This issue may be examined under the rubric of the baseline life conditions hypothesis (Lazarus & DeLongis, 1983; Lazarus & Folkman, 1984). This hypothesis states that in the context of negative life conditions and expectations, positive experiences become more salient than negative ones (Lazarus & Folkman, 1984).

The baseline life conditions in which a person exists at any one time must affect the ways in which they appraise what is occurring around them, and will thus influence the salience of positive and negative events. This was found to be the case in research into the effects of

ageing on the processes involved in stress (Lazarus & DeLongis, 1983). It was found that in a sample of elderly people, good health was more frequently cited as an uplift than it was in a sample of college students. According to Lazarus' hypothesis, therefore, because the elderly group probably experienced less good health than the college group, good health, when it occurred, was appraised as being highly salient.

The original Hassles scale was found to have high test-retest reliability ( $r = 0.95$ ). When the correlations between nine monthly administrations of the Hassles and Uplifts scales were averaged, moderately high reliabilities were found for the frequency of both measures ( $r = 0.79$  for hassles, and  $r = 0.72$  for uplifts). In terms of intensity, the average correlations were lower, indicating moderate reliability ( $r = 0.48$  and  $r = 0.60$ , respectively). These figures suggest that while people were experiencing roughly the same number of hassles over each month, their intensity, or the amount of distress or pleasure associated with them, fluctuated more.

The original data were factor analysed (Lazarus, DeLongis, Folkman & Gruen, 1985), generating eight subscales within the Hassles scale. These scales consisted of - household hassles, health, time pressure, inner concern, environmental, financial responsibility, work, and future security.

Subsequently, the original scales were revised (DeLongis, 1985, cited in DeLongis et al, 1988). Redundant items and terms suggesting psychological and somatic complaints were removed (DeLongis et al, 1988). The rating scale was also changed to a four point scale. These changes resulted in the instrument used in the present study. This scale consists of 53 items which are rated according to the degree to which they have been both a hassle and an uplift for the participant.

The revised Hassles and Uplifts Scale has been used in a number of

research studies which examine various aspects of the nature of hassles and uplifts. Several studies that are relevant to the present research will be briefly reviewed here.

The relationship between hassles, personality and subjective well-being was examined by Zika and Chamberlain (1987). It was found that personality did not act as a significant mediator between hassles and well-being. Chronic daily hassles were found to have a direct effect on subjects' well-being. This is relevant to the present study in that stress is expected to be related to any problems in physical and mental well-being experienced by participants.

Chamberlain and Zika (1990), in their examination of a number of characteristics of hassles, found that the four sample groups in the study endorsed different patterns of hassles, which were consistent with, and appeared to reflect the different social contexts of the groups (Chamberlain & Zika, 1990). This is of relevance to the present study because the two groups involved could be expected to live in different situations. These differences may be reflected in the patterns of hassles endorsed by members of both groups.

Finally, DeLongis, Folkman and Lazarus (1988) found that social support played a moderating role in the relationship between hassles and symptoms and mood disturbance. Lower levels of social support were found to be associated with a higher probability of a positive relationship between stress and physical symptoms and poor mood (DeLongis et al, 1988). This is relevant to the present study, given the hypothesis that lower levels of social support will be associated with higher levels of stress.

In the present study, the Hassles and Uplifts Scale was completed once during the interview.

### **The Ways of Coping Checklist (Revised) (Folkman & Lazarus, 1985)**

This scale was originally devised in 1980 by Folkman and Lazarus, and consisted of 68 coping strategies which were partly drawn from a variety of literature sources (Folkman et al, 1987). These items consisted of both cognitive and behavioural strategies for managing specific stressful encounters (Lazarus & DeLongis, 1983). Respondents were to indicate whether they had used the strategies listed in a specific stressful event.

These strategies can be divided into two rationally derived scales - problem-focussed coping, which seeks to change the "troubled person-environment relationship" (Lazarus & DeLongis, 1983, p 250), and emotion-focussed coping, which alters "the way an encounter is construed or attended to and therefore the emotional reaction to it" (Lazarus & DeLongis, 1983, p 250).

The original scale was factor analysed, producing a problem-focussed scale, five emotion-focussed scales, and a mixed scale consisting of both avoidant and help-seeking strategies (Aldwin, Folkman, Schaefer, Coyne and Lazarus, 1980, cited in Vitaliano et al, 1985). Folkman and Lazarus (1985) revised the original scale, removing redundant items and rewording those that were unclear. Other strategies, such as prayer, and jogging and exercising, were added at the suggestion of past research participants. The response format was also altered from a yes/no response to a four-point likert scale. Responses on this scale are: 0 - not used; 1 - used somewhat; 2 - used quite a bit; and 3 - used a great deal.

A number of factor analyses of the revised scale have been carried out. The most relevant of these was that carried out by Folkman et al (1987), using a community sample of 85 couples. This analysis, in which 15 items were removed due to low factor loadings or lack of conceptual coherence (Folkman et al, 1987), resulted in the generation of eight scales. These scales were labelled: confrontive coping,

seeking social support, accepting responsibility, escape-avoidance, planful problem solving, positive reappraisal, distancing, and self control. The first five scales are similar to those generated in previous research. The scales developed in the 1987 study are unique, however, in that the emotion-focussed self control scale had not been generated before. The differentiation between the two problem solving scales - confrontive coping and planful problem solving - was also novel (Folkman et al, 1987).

The subscales of the original checklist (Folkman & Lazarus, 1980) showed high intercorrelations. The revised scale, however, shows much less overlap between subscales. Intercorrelations for the community sample averaged over five occasions ranged from -0.04 to 0.39 (Folkman et al, 1987). Thus, the subscales in the revised version of the Ways of Coping Checklist are more clearly defined, and thus have higher validity.

In the present study, the Ways of Coping Checklist (Revised) was completed once during the interview. Participants referred to a stressful event involving the head injured person that had occurred during the last month when completing this questionnaire.

### **Health Questions**

This series of questions examined aspects of participants' health since their partner/son/daughter's accident. The issues addressed were: changes in conditions existing before the accident; the occurrence of new conditions since the accident; visiting the doctor for matters concerning oneself; the occurrence of problems for which the doctor was not consulted; and changes in the use of medications. These questions were based loosely around the approach used by Oddy et al (1978). The purpose of these questions was to examine the relationship between the participants' perceived stress and their health, and to give further information on the nature of the differences between the

two groups under study.

### **Role Change Questions**

This set of questions was developed specifically for the present study. The purpose of these questions was to identify the types and degree of changes that had occurred in the roles played by the participants since their partner/son/daughter's head injury. This was to be examined in terms of everyday tasks and activities, thus maintaining consistency with the theoretical base of the present study.

Role changes were assessed with respect to Everyday Activities and the Relationship between the participant and their head injured partner/son/daughter. Everyday Activities were divided into three areas - household activities, finances and social life. Items in this scale included such things as housework, childcare, budgeting, and the amount of time the participant has alone. The questions focussing on changes in the relationship between the participant and their head injured family member covered a number of aspects of the relationship. These included the equality in the relationship, sharing or co-operation between the two, and communication between them.

This set of questions was administered verbally by the researcher. For each item within the four scales, the participant was asked firstly whether there had been any change in this area since their partner/son/daughter's head injury. If change had occurred they were then asked how much change there had been. This was estimated using a five-point likert scale which ranged from 1 - no change to 5 - a great deal of change. Thirdly, participants were asked to give a description of how things had changed in this area.

The data gained from this set of questions was analysed to yield the average degree of change for each item. These averages were then summed to give to average degree of change for each subscale. The

qualitative data was used to identify any recurring themes in terms of changes that had occurred.

#### **The Arizona Social Support Interview Schedule (Barrera, 1981)**

This measure was developed for use in community-based research aimed at better understanding the roles of social support in adjustment to stressful events. The Arizona Social Support Interview Schedule (ASSIS) has three functions in the present study: to gather information about the sources of various kinds of social support; to indicate participants' subjective appraisals of the adequacy of the support they received; and to assess their perceived need for such support. A fourth function - namely a measurement of conflicted network size - was also included in the original measure, but was not used in the present study, as it was not considered appropriate.

Six support functions were rationally derived from various literature sources, and these form the basis for this instrument (Barrera, 1981). These functions are as follows:

- "(1) Material Aid: providing material aid in the form of money and physical objects;
  - (2) Physical Assistance: sharing of tasks;
  - (3) Intimate Interaction: interacting in a non-directive manner such that feelings and personal concerns are expressed;
  - (4) Guidance: offering advice and guidance;
  - (5) Feedback: providing individuals with information about themselves;
  - (6) Social Participation: engaging in social interactions for fun, relaxation, and diversion from demanding conditions"
- (Barrera, 1981, p 75).

In the identification of support network members, many studies (eg Hirsch, 1979, 1980, cited in Barrera, 1981) request participants to

list people who are 'significant' or 'important' to them. This gives an index of network size and composition, but does not identify people who perform specific functions (Barrera, 1981). The ASSIS uses the above social support functions to identify both network size and who performs specific functions, thus overcoming this limitation.

Two indices of network size are generated using the ASSIS - the total available network (the number of people perceived as being available for at least one type of support), and the total utilised network (the number of people reported to have actually provided at least one form of support during the last month) (Barrera, 1981).

Participants are asked to indicate their satisfaction with, and perceived need for, support within each of the identified areas, on three-point likert scales. The satisfaction scale is concerned with how many more opportunities the participant feels they would like for this type of support. The need scale is concerned with the degree to which the participant feels they needed each type of support. All measures except for available network size are taken over the last month.

The ASSIS indices were assessed for their reliability. The preliminary study involved 45 university students, and showed that total utilised network size was stable over time ( $r = 0.88$ ,  $p < 0.001$ ) (Barrera, 1981). The support satisfaction measure was skewed towards high satisfaction scores in this sample, and yielded a moderate test-re-test reliability ( $r = 0.69$ ,  $p < 0.001$ ) and low internal consistency (coefficient alpha = 0.33). The support need measure showed good test-re-test reliability ( $r = 0.80$ ,  $p < 0.001$ ) and moderate internal consistency (coefficient alpha = 0.52) (Barrera, 1981).

The ASSIS was subsequently used to study the role of social support in the adjustment of pregnant adolescents, and used a sample of 86 participants, with a mean age of 17.2 years. This study yielded more satisfactory internal consistency measures of the support satisfaction

(coefficient alpha = 0.50) and support need (coefficient alpha = 0.70) scales (Barrera, 1981). The intercorrelations of the measures of relevance to the present study indicate that they each assess different aspects of social support ( $r = -0.00$  between total utilised network size and support satisfaction;  $r = 0.02$  between total utilised network size and support need; and  $r = -0.55$  between support need and support satisfaction). The last correlation of the three given here is in the expected direction, confirming that the two scales measure different concepts.

In terms of construct validity, support satisfaction was found to be significantly negatively correlated with psychological symptomatology (as measured using the Brief Symptom Inventory (BSI) (Derogatis, 1977, cited in Barrera, 1981)), in terms of the total symptom score, and with individual scores for depression and anxiety. Support need was significantly positively correlated with the total symptom score, and the depression, anxiety and somatisation measures of the BSI. Total utilised network size was not significantly correlated with any of these measures.

From these two studies, it can be seen that the ASSIS is a reliable and valid measure of social network size, support satisfaction and support need. Lower reliabilities gained for the latter two scales may possibly reflect their greater variability in everyday life, rather than a fault in the measures themselves.

In the present study, the ASSIS was verbally administered to participants by the researcher. The results were analysed to indicate: total utilised network size; number of types of support utilised; and the average number of people providing each type of support. The indices of support satisfaction and support need were also calculated.

### Biographical Data

This consisted of a series of verbal questions concerned with identifying the characteristics of the group of participants and their head injured partners/sons/daughters. The characteristics addressed here include age, educational level, employment status, socioeconomic status, the cause of the partner/son/daughter's head injury and participant's relationship to the person with head injury.

Socioeconomic status was assessed both prior to and after the son/daughter/partner's head injury using the Elley-Irving Socio-Economic Index for both women (Irving & Elley, 1977) and men (Elley & Irving, 1985). The scales for both genders range from 1 to 6, with 1 indicating the highest socioeconomic status. This is based on the "median educational and income levels for workers in each specific occupation group" (Elley & Irving, 1985, p 116), as identified in the 1981 Census data.

This section also included a series of questions regarding the information given to the participants at the time of the accident. These questions address the issues of the participants' satisfaction with that information, and whether their perceptions of the information have changed over time.

The Biographical data was used primarily to describe the characteristics of the participant group. It was not used in the analysis of any of the other data gathered, but was used speculatively to a limited extent in the discussion of the results.

## CHAPTER 6 - RESULTS AND PRELIMINARY DISCUSSION

### Introduction

The aims of this study were to examine the degree of Stress experienced by Parents and Partners of people with head injury, and to clarify the differences in perceived Stress between these two groups.

The data was examined from both quantitative and qualitative perspectives. The quantitative perspective was concerned with differences in the numeric values of the issues being examined, that is 'how much', whereas the qualitative perspective focused on the ways the groups differ, namely 'how' rather than 'how much'.

The constructs central to this study, together with the relevant measures used to gain data are shown in Table 6 below. Each construct is presented separately.

**Table 6: Relationship of Constructs and Measures.**

Construct	Measure
Stress	Daily Hassles and Uplifts Scale
Role Change	Role Change Questionnaire
Social Support	Arizona Social Support Interview
Health Problems	Schedule
Coping	Health Problem Questionnaire
Information	Ways of Coping Checklist
	Information Questions
	(Biographical Data)

Within the examination of each construct the results for the Parents and Partners groups combined are examined first. The purpose of this is to establish the overall presence of the variable under consideration in the participant group as a whole. Following this the two groups are examined separately and are then compared.

Some preliminary discussion of the results is included in this chapter where it logically progresses from the presentation of the results.

## Stress

### Introduction

The hypotheses concerning Stress in this study were as follows:

1. Partners will suffer quantitatively more Stress than Parents.
2. There will be qualitative differences between Partners and Parents.

In order to test these hypotheses, the Daily Hassles Scale (DHS) data was examined from different perspectives. The results from the Parents and Partners groups combined and separate were examined, followed by a consideration of the differences between the two groups. Within these three areas, the data was analysed in two main ways. The responses for all of the Hassle items were analysed, followed by a focus on just those items identified as being 'a great deal' of a Hassle.

The DHS items used in each comparison were examined as single items, and were also grouped according to broad categories of Hassle. The 53 items in the DHS were broadly classified into the following categories:

Family (fam)	Relationship With Partner (rel)
Finance (fin)	Work (work)
Home Maintenance/Household (home)	Leisure and Recreation (leisure)
Health and Wellbeing (health)	Environment and External Issues
Miscellaneous (misc)	(environ)

These abbreviations are used throughout the stress section.

The data was viewed from several perspectives. As outlined below, some referred only to the Parents and Partners groups combined, others

pertain to the examination of the two groups separately and to the difference between them. The relevant tables are noted in brackets.

*Responses to all Hassle Items:*

1. The average score for each DHS item was calculated for the respondents as a single Relatives group (Table 7, Page 86).
2. Each respondent was given an overall intensity rating for the DHS as a whole. This was calculated using the formula devised by Kanner et al (1980). This rating was assigned to the appropriate Parents or Partners group and the score averaged (Table 13, Page 93).
3. The average score for each DHS item was calculated for the two groups separately. The two groups were then compared using a one-tailed T test (Table 14, 15, Pages 94, 95).
4. The DHS items most frequently endorsed at any level by both groups were identified and placed in ranked order, indicating those items for which stress was perceived most frequently, as opposed to most intensely (Table 9, 11, Pages 88, 90).

*Items Identified as Being 'a great deal' of a Hassle:*

1. The 10 items endorsed by the greatest percentage of Relatives as a whole were listed in ranked order (Table 8, Page 87).
2. The 10 items endorsed by the greatest percentage of each of the two groups of relatives were listed in ranked order (Table 10, 12, Pages 89, 91).
3. The number of items in each of the categories which were endorsed as being 'a great deal' of a Hassle by more Partners than Parents and vice versa was calculated, and the categories listed in ranked order (Table 16, Page 96).

The average scores referred to above have a possible range of 0 to 3, based on the rating scale used in the DHS. This scale contains four possible responses: 0 - none or not applicable; 1 - somewhat; 2 - quite a bit; and 3 - a great deal in reference to the degree of Stress related to each of the scale items.

## Results

### Parents and Partners Groups Combined

#### *Responses to all Hassle Items*

In terms of responses to all the Hassle items, Table 7 shows the ranked order of the nine DHS items with the highest average Stress ratings for the Parents and Partners groups combined. The top nine items were chosen because the item with the next highest average rating was equal with a number of other items, and it made little sense to include this information here.

**Table 7:** Rank Order and Average Scores of DHS items for Parents and Partners groups combined.

Rank Order	Item and Category	Average
1	(9) Family related obligations (fam)	1.52
2	(15) Your workload (work)	1.42
3	(6) Health/wellbeing of a family member (fam)	1.39
4	(18) Enough money for necessities (fin)	1.19
5=	(42) Home repairs (home)	1.16
5=	(47) Amount of free time (leisure)	1.16
7=	(4) Your spouse or partner (rel)	1.13
7=	(5) Time spent with family (fam)	1.13
7=	(33) The weather (environ)	1.13

Items from the Family category were the most prominent, with the remainder of the items being divided evenly between six of the seven remaining categories.

As a whole, the average scores indicate that these items were, on average 'somewhat' of a Hassle for the combined group of respondents, based on the four-point response scale used in the DHS. This indicates that a degree of Stress existed for Parents and Partners combined.

*Items Identified as Being 'A Great Deal' of a Hassle*

The 10 items most frequently endorsed as being 'a great deal' of a Hassle for the combined Parents and Partners groups are shown in Table 8. The areas of high Stress for the participants as a whole were Work, Family and Finance, as shown by the ranked order and the number of items from each category.

**Table 8: The ten DHS items most frequently endorsed as 'a great deal' of a Hassle by Parents and Partners groups combined**

Rank Order	Item and Category	Percentage
1	(15) Your workload (work)	58.6%
2	(6) Health or wellbeing of a family member (fam)	50.9%
3=	(18) Enough money for necessities (fin)	44.1%
3=	(20) Enough money for emergencies (fin)	44.1%
5	(9) Family-related obligations (fam)	43.2%
6	(51) Legal matters (misc)	41.9%
7=	(14) The nature of your work (work)	39.8%
7=	(41) Housework (home)	39.8%
9	(47) Amount of free time (leisure)	37.6%
10	(45) Taking care of paperwork (home)	36.4%

Parents and Partners

This section examines the Stress experienced by both Parents and Partners groups.

When the ten DHS items most frequently endorsed by each group were examined, both groups showed different patterns of endorsement. These patterns were repeated when the ten DHS items most frequently endorsed by each group as being 'a great deal' of a hassle were examined.

*Patterns of Stress - Parents*

Table 9 shows the ten most frequently endorsed DHS items for the Parents group. The most frequently reported individual item was that

concerned with Family-related obligations. In terms of categories, the most highly represented were Family, Environmental/External Issues and Health and Wellbeing.

**Table 9: Ten most frequently endorsed DHS items for the Parents group.**

Rank Order	Item and Category	Percentage
1	(9) Family-related obligations (fam)	83.33%
2=	(5) Time spent with family (fam)	72.22%
2=	(6) Health/wellbeing of a family member (fam)	72.22%
4=	(1) Your children (fam)	66.66%
4=	(15) Your workload (work)	66.66%
4=	(36) Political or social issues (environ)	66.66%
7=	(29) Exercise(s) (health)	61.11%
7=	(32) Your physical abilities (health)	61.11%
7=	(32) The weather (environ)	61.11%
7=	(34) News events (environ)	61.11%

Table 10 shows the nine DHS items most frequently endorsed as being 'a great deal' of a Hassle by the Parents group. Again, only the top nine items were included here because there were a number of items that ranked as tenth equal. The item most frequently endorsed as being most intense was that concerning the 'Health or wellbeing of a family member'. When the data presented in Table 10 is examined in terms of DHS item categories, it is evident that Family and Health and wellbeing were again important as sources of Stress. The area of Work was also important when these, the most intense Hassles are considered.

**Table 10:** Nine DHS items most frequently endorsed as 'a great deal' of a Hassle by the Parents group.

Rank Order	Item and category	Percentage
1=	(6) Health/wellbeing of a family member (fam)	27.8%
1=	(9) Family-related obligations (fam)	27.8%
1=	(15) Your workload (work)	27.8%
4	(47) Amount of free time (leisure)	22.2%
5=	(1) Your children (fam)	16.7%
5=	(14) The nature of your work (work)	16.7%
5=	(24) Your smoking (health)	16.7%
5=	(29) Exercise(s) (health)	16.7%
9	(21) Enough money for extras (fin)	11.2%

*Patterns of Stress - Partners*

Table 11 shows the eight most frequently endorsed DHS items for the Partners group overall. The most frequently endorsed item was that of 'Your spouse or partner', which was reported as being a Hassle by all members of this group. In terms of categories, Finance and Home Maintenance/Household were the greatest sources of Stress when the data was examined in this way.

**Table 11:** Eight most frequently endorsed DHS items for the Partners group.

Rank Order	Item and Category	Percentage
1	(4) Your spouse/partner (rel)	100.00%
2=	(18) Enough money for necessities (fin)	84.61%
2=	(21) Enough money for extras (fin)	84.61%
4=	(15) Your workload (work)	76.92%
4=	(20) Enough money for emergencies (fin)	76.92%
4=	(42) Home repairs (home)	76.92%
4=	(45) Taking care of paperwork (home)	76.92%
4=	(51) Legal matters (misc)	76.92%

The pattern noted in the data shown in Table 11 is continued in Table 12, which presents the eleven items most frequently endorsed as being 'a great deal' of a Hassle by the Partners group. Finance was again the most prevalent category, while the importance of the Home Maintenance/Household category as a source of Stress was emphasised.

**Table 12:** Eleven DHS items most frequently endorsed as being 'a great deal' of a Hassle by the Partners group.

Rank Order	Item and Category	Percentage
1=	(18) Enough money for necessities (fin)	38.5%
1=	(20) Enough money for emergencies (fin)	38.5%
1=	(42) Home repairs (home)	38.5%
4=	(15) Your workload (work)	30.8%
4=	(45) Taking care of paperwork (home)	30.8%
4=	(51) Legal matters (misc)	30.8%
7=	(14) Nature of your work (work)	23.1%
7=	(6) Health/wellbeing of a family member (fam)	23.1%
7=	(21) Enough money for extras (fin)	23.1%
7=	(40) Cooking (home)	23.1%
7=	(41) Housework (home)	23.1%

### Comparison Between Parents and Partners

The Stress experienced by the two groups of relatives was compared in a number of ways in order to test the hypotheses that quantitative and qualitative differences exist between the two.

The two groups were compared in terms of their respective Average Intensity scores, computed using the formula devised by Kanner et al (1980), as outlined in the footnote below.<sup>1</sup> The two groups were also compared with regard to the range of average scores on each item.

---

<sup>1</sup>This statistic is calculated in the following manner: "cumulated severity, the sum of the 3-point ratings ... divided by the frequency" (Kanner et al, 1980, p9), the frequency being a simple count of the number of items endorsed. This can also be represented by the following equation, in which N1, N2 and N3 are the number of items endorsed at level 1, 2 and 3 respectively.

$$\text{Average Intensity} = \frac{(1 \times N1) + (2 \times N2) + (3 \times N3)}{N1 + N2 + N3}$$

From this formula, and average intensity score is gained for each subject. This statistic has a range of 0 - 3.

Table 13 shows that the intensity of Stress was higher for the Partners group, which also showed a greater range of scores than the Parent group. The DHS stress items with the highest and lowest average scores were different for the groups, although both the Partners lowest and highest scores were both from the Finance category.

**Table 13: Average Intensity of Stress for Parents and Partners Groups, Range of Average Scores and Highest and Lowest DHS Items.**

Group	Average Intensity Stress	Range (difference)	Items Accounting For	
			Lowest Average Stress	Highest Average Stress
Parents	1.56	1.00 - 2.23 (1.23)	(25)Your drinking (health)  (35)Your environ- ment (environ)	(9) Family obligations (fam)
Partners	1.69	1.15 - 2.53 (1.38)	(23)Investments (fin)	(8) Enough money for necessities (fin)

When the group averages for each of the DHS items were compared, Partners experienced more Stress than Parents on 36 of the 53 Hassles items. Eleven of these differences were significant. These items, listed with their relevant category, average score and rank order are shown in Table 14. Parents experienced greater Stress than Partners on 14 of the 53 items, but none of these differences reached significance.

**Table 14:** Rank Order of Stress Items and Categories where Partners identify significantly more Stress than Parents.

Rank Order	Item and Category	Partners Average	Parents Average
1	(18) Enough money for necessities (fin)	1.85	0.72
2	(42) Home repairs (home)	1.69	0.78
3=	(4) Your spouse/partner (rel)	1.61	0.78
3=	(20) Enough money for emergencies (fin)	1.61	0.67
3=	(21) Enough money for extras (fin)	1.61	0.72
3=	(45) Taking care of paperwork (home)	1.61	0.67
7	(14) The nature of your work (work)	1.54	0.78
8	(51) Legal matters (misc)	1.46	0.50
9	(53) Social commitments (leisure)	1.15	0.39
10	(10) Your friends (leisure)	1.00	0.11
11	(2) Your parents or parents-in-law (fam)	0.92	0.39

In general, the significant and non-significant items that Partners reported more Stress in than Parents came primarily from the Home Maintenance/Household category, which accounted for eight items, and Work, which accounted for five. The items on which Parents reported more Stress than Partners were equally divided between the Family, Health and Wellbeing and Environmental and External Issues categories. A summary of the degree of endorsement these items represent in their various categories is shown in Table 15 which shows that the ranked order of the nine DHS items categories was very different, indicating qualitative differences in the Stress experienced by the two groups.

**Table 15: Rank order of Categories of DHS items endorsed as being more stressful by Parents than by Partners, and vice versa.**

Partners > Parents		Parents > Partners	
Rank Category	No. Items	Rank Category	No. Items
1 Home Maintenance/ Household	8 (8)	1= Health and Well- being	3 (9)
2 Work	5 (7)	1= Family	3 (6)
3= Finance	4 (6)	1= Environmental/Ex- ternal Issues	3 (5)
3= Leisure and Rec- reation	4 (6)	4= Work	2 (7)
3= Health and Well- being	4 (9)	4= Leisure and Rec- reation	2 (6)
6= Relationship with Partner	3 (4)	6 Finance	1 (6)
6= Miscellaneous	3 (3)	7= Home Maintenance/ Household	0 (8)
6= Family	3 (6)	7= Relationship with Partner	0 (4)
9 Environmental/Ex- ternal Issues	2 (5)	7= Miscellaneous	0 (3)

This is reinforced by the data presented in Tables 9 and 11 in which both quantitative and qualitative information is shown. These two tables contain the ten most frequently endorsed DHS items by each group. When the two sets of data are compared, it can be seen that the most stressful categories for the Parents group were Family, Environmental/External Issues and Health and Wellbeing. Partners, on

the other hand, endorsed items from the Finance and Home Maintenance/Household categories as being their greatest sources of Stress.

When the intensity of the Stress experienced by the two groups is examined, using only those items endorsed as being 'a great deal' of a Hassle in the analysis, further patterns of difference between the two groups are apparent. This provides further qualitative and quantitative information about the Stress experienced by the participants in the present study.

The percentages of each group endorsing each DHS item as being 'a great deal' of a Hassle were compared. Table 16 shows the number of items in each category which were endorsed as being 'a great deal' of a Hassle by a greater percentage of Partners than Parents, and by a greater percentage of Parents than Partners.

**Table 16:** Ranked order of DHS categories for which more Partners than Parents, and more Parents than Partners, endorsed items as being 'a great deal' of a Hassle.

% Partners > % Parents			% Parents > % Partners		
Rank	Category	No. Items	Rank	Category	No. Items
1	Home Maintenance/ household	5 (8)	1	Health and Well- being	4 (9)
2=	Finance	4 (6)	2	Family	3 (6)
2=	Work	4 (7)	3=	Environmental/Ex- ternal Issues	2 (5)
4=	Family	3 (6)	3=	Finance	2 (6)
4=	Health and Well- being	3 (9)	3=	Work	2 (7)
4=	Leisure and Rec- reation	3 (6)	3=	Leisure and Rec- reation	2 (6)
7=	Relationship With Partner	2 (4)	7=	Relationship With Partner	1 (4)
7=	Environmental/Ex- ternal Issues	2 (5)	7=	Home Maintenance/ Household	1 (8)
7=	Miscellaneous	2 (3)	9	Miscellaneous	0 (3)

Table 16 shows that, again, Home Maintenance/Household, Finance and Work figured prominently for the Partners group, while Health and Wellbeing and Family were areas of Stress for Parents. In terms of quantitative analysis, it can be seen from Table 14 that there were a larger number of items endorsed as being 'a great deal' of a Hassle by more Partners than Parents. This indicates that Partners, in more frequently endorsing a high level of Stress, experienced quantitatively more Stress than the Parents group.

When the data presented in Tables 10 and 12 are compared, further support for the existence of qualitative differences between the groups is found. These two tables refer to the ten DHS items most frequently endorsed as 'a great deal' of a Hassle by each group. Different patterns of endorsement are apparent in these two tables, showing that the main sources of Stress for parents were Family and Health and Wellbeing. Partners, on the other hand, showed their main sources of Stress to be Finance and Home Maintenance and Household.

### Summary

The results gained from the data concerning Stress can be summarised in terms of the Parents and Partners groups combined, and the comparison between the two groups.

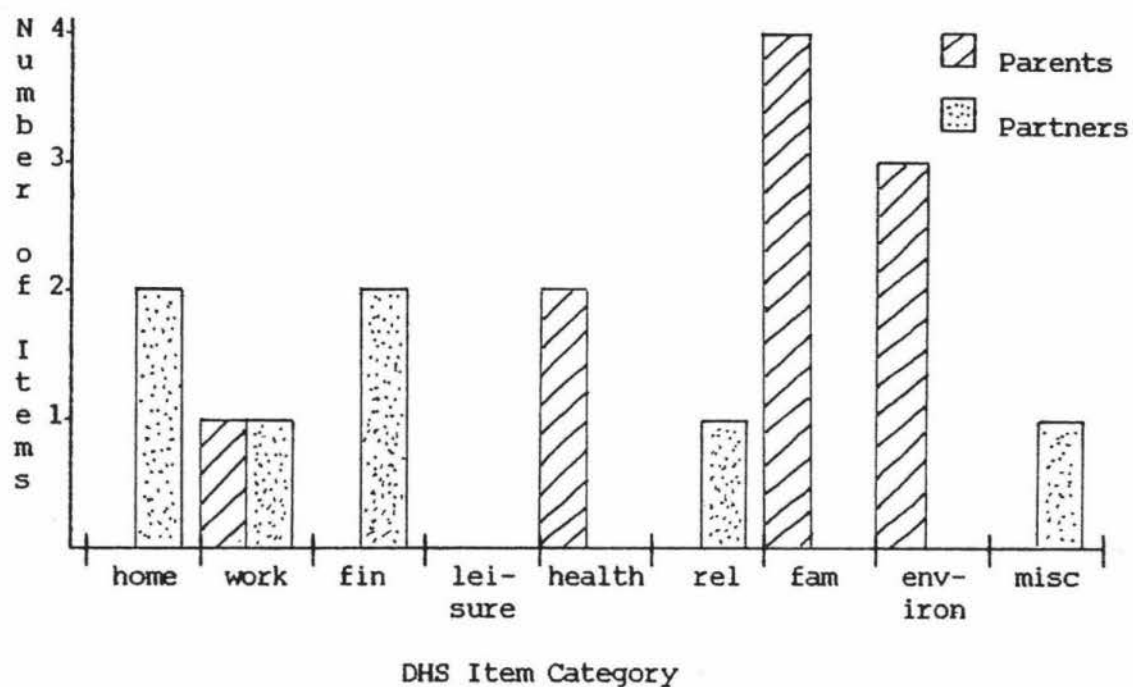
#### *Parents and Partners Groups Combined*

For the participants as a single group, the Family was the most prominent area of Stress. The areas of Work and Finance also contributed to the Stress experienced by the participants of the present study. The other categories of DHS items examined here contributed uniformly but less than the abovementioned areas.

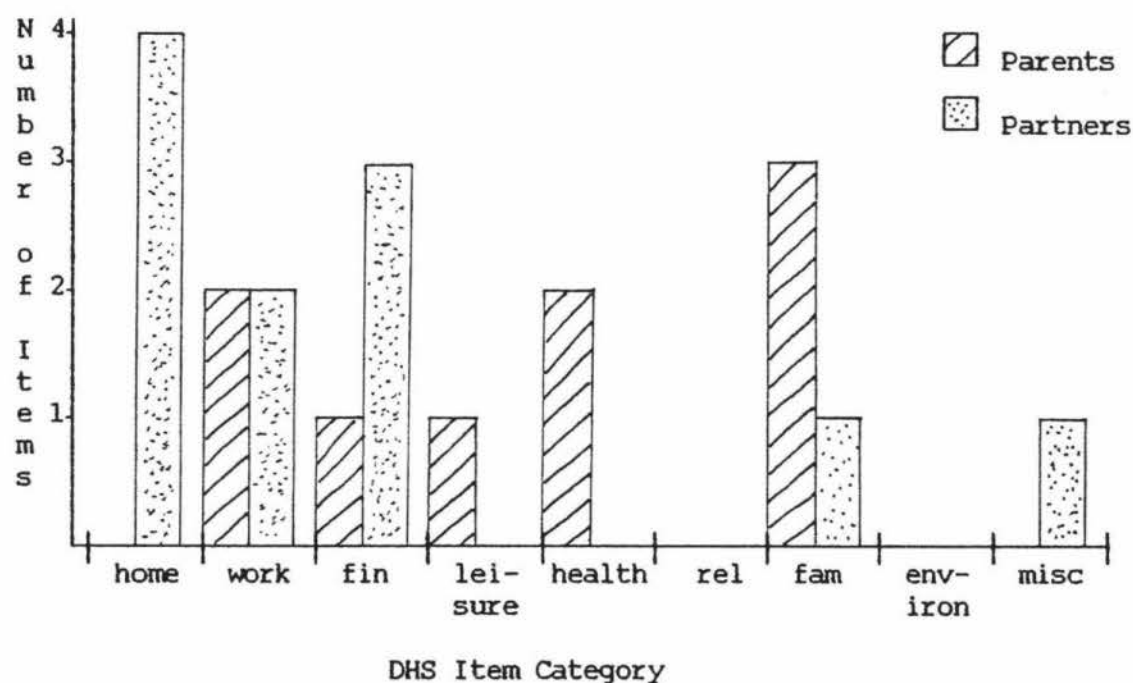
*Comparison Between Parents and Partners*

In terms of quantitative differences between the two groups, Partners showed higher levels of Stress than Parents both in terms of overall average intensity and having higher average scores on a majority of DHS items as illustrated in Table 13. When the data concerning the Hassle items endorsed as being 'a great deal' of a Hassle is considered, as presented in Table 14, it can be seen that more of these items were endorsed by a greater percentage of Partners than Parents than vice versa. This indicates that more Partners than Parents experienced a high degree of Stress. This provides support for Hypothesis 1, which was concerned with quantitative differences between the two groups.

Qualitatively, there were differences between the two groups in the pattern of DHS item endorsements. Figures 5 and 6 illustrate the nature of these differences. Figure 5 shows the number of items from each category that contribute to the items most frequently endorsed by each group. This data was taken from Tables 9 and 11, and indicates the relative importance of each category in terms of the frequency of endorsement. Figure 6 presents the number of items from each category that contribute to the items most frequently endorsed as 'a great deal' of a Hassle by both groups. This gives a summary of the data from Tables 10 and 12, and indicates the relative importance of each category in terms of the intensity of experienced Stress.



**Figure 5:** The number of items from each category that make up the most frequently endorsed group of items for the Parents and Partners groups.



**Figure 6:** The number of items from each category that contribute to the items most frequently endorsed as 'a great deal' of a Hassle by the Parents and Partners groups.

When figures 5 and 6 are considered together, it can be seen that the areas indicated as being sources of Stress for Partners were primarily Home Maintenance and Household and Finance. Work also impacted on their experienced Stress, while Parents indicated strongly that the Family was the primary source of Stress, with Health and Wellbeing, Environmental and External Issues and Work also playing an important role.

The results obtained therefore provide support for the hypothesis that Parents and Partners experience qualitative differences in their respective sources of stress.

### Role Change

#### **Introduction**

Role Change was examined in the present study because of its possible relationship with the Stress experienced by the participants. The hypotheses concerning Role Change in the present study were as follows:

1. That Partners experience quantitatively more Role Change than Parents.
2. That there will be qualitative differences in Role Change between Parents and Partners.
3. That a positive correlation will be found between Role Change and Stress.

In order to test these hypotheses, the data from the Role Change Questionnaire (RCQ) was analysed in several ways. As with the examination of the Stress data, the results from the participants as a whole were examined, followed by the Parents and Partners groups separately. A comparison was then made between these two groups.

Within these three main areas of focus, the Role Change data was

examined in the following ways:

1. An average score for the entire RCQ was obtained for the entire group of participants and the two separate groups.
2. Average scores for each RCQ item were calculated for the Parents and Partners groups combined and separate.
3. The RCQ items were divided into four subsections concerned with role change in different areas. Average scores for each subsection were then calculated.

The average scores referred to above have a possible range of 0 - 4, based on the rating scale used in administering the RCQ. This scale was changed from 1 - 5 for analysis purposes.

The four categories of role change within the RCQ are as follows:

Household (house)

Financial (fin)

Social (soc)

Relationship With Head Injured Person (rel)

A third area, the correlation between Stress and Role Change was also examined briefly. Again, this was viewed in terms of the Parents and Partners groups combined and separate.

## Results

### Parents and Partners Groups Combined

The overall average score for the RCQ was calculated for the combined Parents and Partners groups, and was found to be 0.99. Within the range of 0 - 4 this indicated a low level of overall Role Change.

The average scores for each individual RCQ item were calculated and the ten items with the highest averages were listed in ranked order. The data presented in Table 17 shows that the RCQ category in which the most changes in roles took place was the participants Relationship With the Head Injured Person, followed by Social functioning. The average scores for each item are still relatively low on the scale of 0 - 4, but do indicate areas of greatest change for the participants group as a whole.

**Table 17: Eleven RCQ items with the highest average scores for Parents and Partners groups combined.**

Rank Order	Item and Category	Average
1	(22) Similarity of the relationship now and before the head injury (rel)	1.84
2=	(19) Communication between the respondent and the head injured person (rel)	1.65
2=	(20) The closeness of your relationship (rel)	1.65
4	(16) Equality in the relationship (rel)	1.61
5	(12) Amount of free time alone (soc)	1.58
6=	(13) Amount of free time with head injured person (soc)	1.48
6=	(23) Closeness of the whole family (rel)	1.48
8	(17) Who dominates in various areas (rel)	1.42
9	(4) Childcare (house)	1.32
10=	(14) General social activities (soc)	1.26
10=	(21) Sharing or co-operation (rel)	1.26

The average Role Change scores for each of the four categories of change were also calculated for the participants as a single group. This data is presented in Table 18. It shows that, in terms of categories, the greatest Role Change experienced by Parents and Partners combined was in their Relationship With the Head Injured

Person followed by change in the Social area. The Financial area showed the least degree of change. The data presented in Table 17 indicates that Role Changes did occur for the participants as a whole, more so in some areas than others.

**Table 18:** Average scores on the four Role Change categories for Parents and Partners combined.

Category	Average
Financial	0.10
Household	0.81
Social	1.14
Relationship With Head Injured Person	1.32

When the correlation between Stress and Role Change was examined for the combined Parents and Partners groups, a moderate, statistically significant relationship was found ( $r = 0.6320$ ,  $p < 0.001$ ,  $d o f = 29$ ). This provides support for the hypothesis that these two variables would positively correlate.

### Parents and Partners

This section provides an overview of the Role Changes experienced by the Parents and Partners groups separately.

#### *Role Change - Parents*

The ten RCQ items with the highest average scores for the Parents group were listed in ranked order, and are presented in Table 19. Relative to the overall range, these scores show that Role Changes were experienced by the Parents group. The area in which most of these changes took place overall was that of their relationship with their head injured son/daughter, although the item with the highest average

score came from the Social category. The Social and Household areas both accounted for an equal but small degree of change in terms of the number of items that came from each category in this Table.

**Table 19:** Ten RCQ items with the highest average scores for the Parents group.

Rank Order	Item and Category	Average
1	(12) Amount of free time alone (soc)	2.00
2	(22) Similarity of the relationship now and before the head injury (rel)	1.72
3	(23) Closeness of the whole family (rel)	1.61
4	(19) Communication between the respondent and the head injured person (rel)	1.55
5	(13) Amount of free time with the head injured person (soc)	1.50
6=	(4) Childcare (house)	1.44
6=	(16) Equality in the relationship (rel)	1.44
8=	(1) Housework (house)	1.39
8=	(17) Who dominates in various areas (rel)	1.39
10	(20) The closeness of your relationship (rel)	1.33

The average Parents group scores were calculated for the four categories of Role Change within the RCQ and are shown in Table 20. As with the participants as a whole, the categories in which the greatest and least change occurred were Relationship With the Head Injured Person and Financial respectively. These averages indicate that Role Changes existed for the Parents group in the Social and Relationship areas, but did not have much impact in the Household and Financial areas.

**Table 20:** Average scores on the four role change categories for the Parents group.

Category	Average
Financial	0.30
Household	0.72
Social	1.11
Relationship With Head Injured Person	1.14

The correlation between Stress and Role Change was examined for the Parents group. These two variables were found to have a low positive correlation that was non-significant ( $r = 0.3534$ ,  $d o f = 16$ ). This result is congruent with the hypothesis that a positive correlation exists between these two variables.

*Role Change - Partners*

Data from the Partners group was examined in the same way as that of the Parents. The ten ROQ items with the highest average scores were placed in ranked order, as shown in Table 21. Again, items from the Relationship area accounted for the greatest proportion of these, making up seven of the ten items.

**Table 21:** Ten ROQ items with the highest average scores for the Partners group.

Rank Order	Item and Category	Average
1	(20) The closeness of your relationship (rel)	2.08
2=	(14) General social activities (soc)	2.00
2=	(22) Similarity of the relationship now and before the head injury (rel)	2.00
4	(16) Equality in the relationship (rel)	1.84
5	(19) Communication between the respondent and the head injured person (rel)	1.77
6=	(18) Your sexual relationship (rel)	1.69
6=	(21) Sharing or co-operation (rel)	1.69
8	(13) Amount of free time with the head injured person (soc)	1.46
9	(8) Budgeting (fin)	1.38
10	(23) Closeness of the whole family (rel)	1.31

The average scores for each category are presented in Table 22, and show that the Partners Relationship With the Head Injured Person was the area in which the greatest average change took place. Change was evident in the Social area and the Household area. Relative to the overall range, the individual item scores and the average category scores indicated the presence of role change in certain areas.

**Table 22:** Average scores on the four role change categories for the Partners group.

Category	Average
Financial	0.76
Household	0.92
Social	1.17
Relationship With Head Injured Person	1.56

A low to moderate positive correlation between Stress and Role Change was found for the Partners group ( $r = 0.4335$ ,  $d o f = 11$ ). This was not statistically significant. This provides support for Hypothesis 4, which stated that a positive correlation would be found.

#### Comparison Between Parents and Partners

Comparisons of the Role Change data were made between the Parents and Partners groups, to test whether quantitative and qualitative differences existed between the two groups, as suggested by the first and second Role Change hypotheses.

A comparison was made between the overall RCQ average scores and the range of average individual RCQ item scores for the two groups. This data is presented in Table 23. It can be seen that the Partners group had a higher overall average score than the Parents, but the difference

between the two was not significant. In terms of the range of average item scores, both the lowest and highest Partners scores were of a greater magnitude than those of the Parents group.

**Table 23:** Overall average ROQ scores and range of average ROQ item score for Parents and Partners groups.

Group	Overall Average	Range of Item Scores (difference)
Parents	0.86	0.05 - 2.00 (1.95)
Partners	1.17	0.23 - 2.08 (1.85)

When the data presented in Tables 19 and 21 concerning the top ten ROQ items for the two groups is compared it can be seen again that, in terms of the magnitude of the average scores of these items, Partners experienced a quantitatively greater degree of Role Change than Parents.

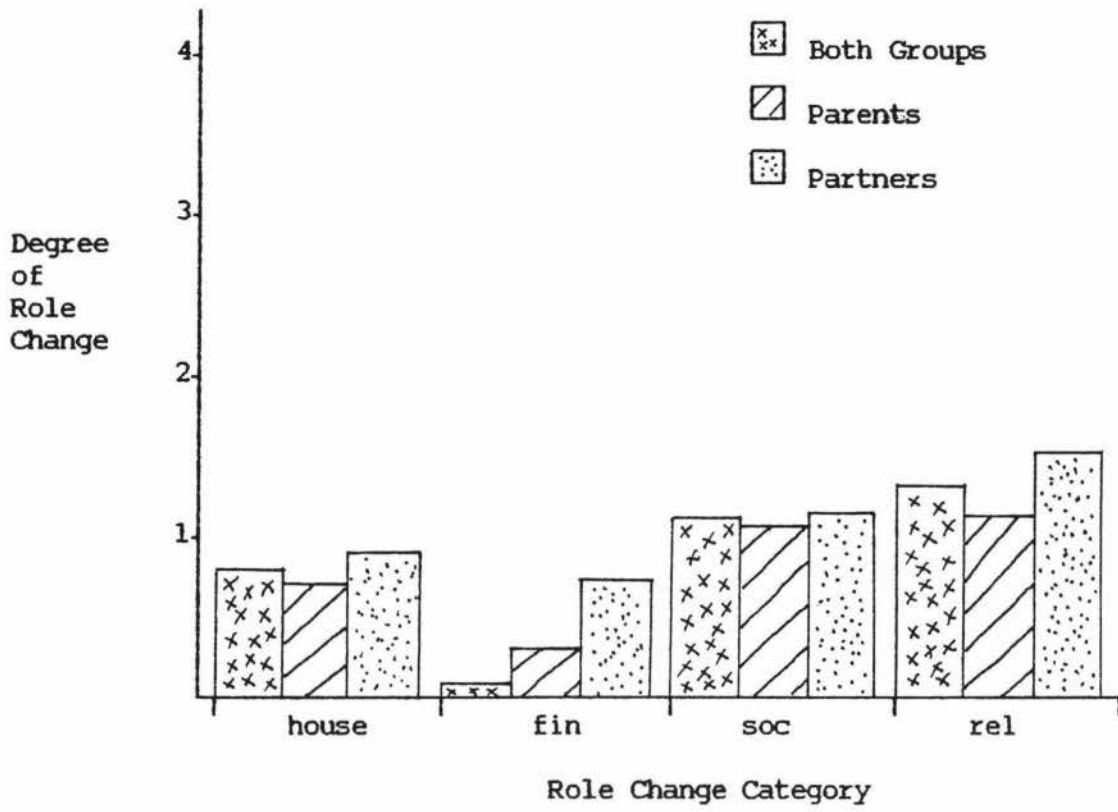
The data presented in Tables 20 and 22, concerning the average scores for the four Role Change categories, also reflects this pattern. The Partners average category scores were greater than those of the Parents group. When the differences between these figures were examined using a one-tailed T test, only the difference between the average scores on the Financial category was found to be significant ( $p < 0.05$ ; d o f 29).

These results support the hypothesis that Partners experience quantitatively more Role Change than Parents, both in terms of a summary figure of Role Change and in the four identified categories of change.

In terms of qualitative differences between the two groups, the pattern of reported Role Change differed very little in general terms. Both groups reported the most change in the area of their Relationship With the Head Injured Person, and the least in the Financial area. This was reflected in the data concerned with the top ten items and the average category scores.

When the individual items in Tables 19 and 21 are examined it can be seen that there were some differences in the items contained in the two tables and in their rank order. However, in overall terms the hypothesis that qualitative differences in Role Change would exist between the two groups was not supported by the data obtained.

Figure 7, on the following page, summarises the quantitative and qualitative differences between Parents and Partners and provides comparison between the two groups separated and combined.



**Figure 7:** Degree of Role Change within each category for Parents and Partners groups combined and separate.

## Social Support

### Introduction

Like Role Change, Social Support was examined in the present study because of its possible relationship to the Stress experienced by Parents and Partners of people with head injury. The hypotheses concerning Social Support were as follows:

1. That Parents would receive quantitatively more Social Support than Partners.
2. That Parents Social Support would differ qualitatively from Partners Social Support in terms of the sources and types of support received.
3. That there would be a negative correlation between Stress and all indices of Social Support, except need for Social Support which would be positively correlated.

As with the examination of Stress and Role Change, the three main areas of focus were the participants group as a whole, the Parents and Partners groups separately, and the differences between Parents and Partners.

Within these three areas of focus, the data obtained from the Arizona Social Support Interview Schedule (ASSIS) generated five indices of Social Support, namely:

- Network size
- Types of support
- Sources of support
- Satisfaction with support
- Need for support

These indices were examined in terms of support received, rather than potential support, and the following data was analysed:

1. The average number of people who provided support overall.

2. The average number of types of support received.
3. The average number of people providing each type of support.
4. The overall average satisfaction with the support received.
5. The overall need for support.
6. The ten most frequently used sources of support.

The final area examined was that of the correlation between Stress and Social Support. This too was looked at in terms of the participants as a whole and the two separate Parents and Partners groups.

## Results

### Parents and Partners Groups Combined

Table 24 contains a summary of the average number of people support was received from, types of support received, satisfaction with support and need for support, as well as the ranges of these statistics, for the Combined Parents and Partners groups.

**Table 24:** Averages and ranges of the number of people providing support, types of support provided, satisfaction with support and need for support for Parents and Partners groups combined.

Index of Support	Average	Range
Number of people providing support	5.48	1 - 10
Number of types of support provided	4.67	0 - 6
Overall satisfaction with support	2.33	1 - 3
Overall need for support	2.12	1 - 3

It can be seen that the participants as a group received support of a number of kinds from a number of people. The number of people who

provided support was, on average, around the mid-point of the range, and the varieties of support received were well above the mid point. On average the satisfaction with the support received was quite high, as was the need for support.

The ASSIS contains six identified areas of support, and the average number of people providing each type of support was calculated, and the areas placed in ranked order. This data is shown in Table 25. It can be seen that the area in which the most support was received (in terms of the number of people providing it) was that of sharing Private Feelings. Positive Feedback and Physical Assistance were the areas in which the least support was given.

**Table 25:** Average numbers of people providing each identified type of support for Parents and Partners groups combined.

Rank Order	Type of Support	Average
1	Private Feelings	2.84
2=	Material Aid	2.16
2=	Social Participation	2.16
4	Advice	1.58
5	Physical Assistance	0.93
6	Positive Feedback	0.29

The correlations between Stress and indices of Social Support were calculated, and are presented in Table 26. The correlations between Stress and the number of people providing support and the types of support provided were both in the expected direction, while the remaining two correlations did not support this hypothesis. The correlations are all of a very low magnitude. Therefore, these results provide only very limited support for Hypothesis 3.

**Table 26: Correlations between Stress and Social Support indices for Parents and Partners groups combined.**

Social Support Index	r	d o f
Number of people providing support	-0.0039	29
Number of types of support provided	-0.0405	29
Overall satisfaction with support	0.2925	29
Overall need for support	0.0662	29

### Parents and Partners

The data gathered from the Parents and Partners groups was examined separately.

#### *Social Support - Parents*

Table 27 gives a summary of the averages and ranges of the number of people providing support, the number of types of support provided, satisfaction with and need for support for the Parents group. These results show that, in terms of the ranges, the number of people providing support and the number of types of support provided were quite high. Parents satisfaction with the support they received was also high, and their level of need was only slightly lower than this.

**Table 27:** Averages and ranges of the number of people providing support, the number of types of support, satisfaction with support and need for support for the Parents group.

Index of Support	Average	Range
Number of people providing support	5.28	1 - 8
Number of types of support provided	5.22	0 - 6
Overall satisfaction with support	2.39	1 - 3
Overall need for support	2.17	1 - 3

The number of people providing each type of support was calculated for the Parents group, and the support types placed in ranked order. This data is contained in Table 28, and indicates that the area in which the greatest support was experienced by Parents was that of Private Feelings. The area in which the least support was given was that of Positive Feedback.

**Table 28:** Average numbers of people providing each identified type of support for the Parents group.

Rank Order	Type of Support	Average
1	Private Feelings	2.94
2	Social Participation	2.11
3	Material Aid	2.00
4	Advice	1.55
5	Physical Assistance	0.89
6	Positive Feedback	0.22

The sources of support identified by parents were placed in ranked order according to the percentage of the Parents group that received support from them. This data is presented in Table 29, and gives an indication of the main sources of support for this group.

**Table 29:** Ranked order of sources of support for the Parents group.

Rank Order	Source of Support	Percentage
1=	Spouse/partner	55.55
1=	Child(ren)	55.55
1=	Whole family	55.55
4=	Friend/friends in general	38.88
4=	Work colleagues	38.88
6=	In-laws	22.22
6=	Neighbours	22.22
8	Own doctor	16.66
9=	Siblings	11.11
9=	Parent(s)	11.11
9=	Appropriate authorities	11.11

Table 29 shows that the most common sources of support for Parents were their spouse or partner, children and whole family. Friends and work colleagues also ranked quite prominently. It is interesting to note that neighbours ranked above the siblings and parents of respondents in this group.

When the correlations between Social Support indices and Stress were examined for the Parents group, it was found that all the correlations were in the opposite direction to that which was hypothesised. The correlations were all of low and moderate magnitude and none were significant. These are shown in Table 30. These results provide no support for Hypothesis 3.

**Table 30:** Correlations between Stress and Social Support indices for the Parents group.

Social Support Index	r	d o f
Number of people providing support	0.2356	29
Number of types of support provided	0.4706	29
Overall satisfaction with support	-0.3778	29
Overall need for support	0.4452	29

*Social Support - Partners*

Table 31 contains the data for the Partners group concerning the averages and ranges of the number of people providing support, the types of support provided, satisfaction with support and need for support. It shows that the number of people providing support was in the lower half of the range, and the number of types of support was just above the halfway point of its range. Satisfaction was slightly higher than need for support for the Partners group.

**Table 31:** Averages and ranges of the number of people providing support, the types of support provided, satisfaction with support and need for support for the Partners group.

Index of Support	Average	Range
Number of people providing support	5.76	2 - 10
Number of types of support provided	3.92	0 - 6
Overall satisfaction with support	2.25	1 - 3
Overall need for support	2.05	1 - 3

When the average number of people providing each type of support was determined, it was found that the area in which the greatest support was provided was that of Private Feelings. The next area in ranked order was that of Material Aid. The area in which the least support was given was that of Positive Feedback. This information is presented in Table 32.

**Table 32:** Average numbers of people providing each identified type of support for the Partners group.

Rank Order	Type of Support	Average
1	Private Feelings	2.69
2	Material Aid	2.38
3	Social Participation	2.23
4	Advice	1.61
5	Physical Assistance	1.00
6	Positive Feedback	0.38

The sources of support for Partners were placed in ranked order according to the percentage of the Partners group that received support from each source. This information is shown in Table 33.

**Table 33:** Rank order of sources of support for the Partners group.

Rank order	Source of Support	Percentage
1=	Friend/friends in general	69.92
1=	Spouse/partner	69.92
3=	Children	30.76
3=	Parent(s)	30.76
3=	Whole family	30.76
6=	In-laws	23.07
6=	Work colleagues	23.07
8=	Own doctor	15.38
8=	Sibling(s)	15.38
8=	Neighbours	15.38
8=	Rehabilitation Co-ordinator	15.38
8=	Miscellaneous sources	15.38

Table 33 indicates that the greatest sources of support for the Partners group were friends, spouse or partner and the respondent's children. There was a large drop to the next most common sources of support, namely children, parents and the family as a whole. The lowest ranked family members here were the respondents siblings, who ranked eighth equal.

The correlations between Stress and Social Support indices were examined for the Partners group, and these are presented in Table 34. This data shows that half of the correlations supported the hypothesis that Stress would correlate negatively with Social Support, and positively with need for Social Support. Thus there is not conclusive support for Hypothesis 3 in the data from the Partners group.

**Table 34:** Correlations between stress and Social Support indices for the Partners group.

Social Support Index	r	d o f
Number of people providing support	-0.3603	29
Number of types of support provided	-0.4524	29
Overall satisfaction with support	0.3423	29
Overall need for support	-0.3224	29

#### Comparison Between Parents and Partners

The differences in Social Support between the Parents and Partners groups were examined using the indices contained in the previous section.

When the data in Tables 27 and 30 is compared, it can be seen that Parents showed higher averages in terms of the number of types of

support provided, satisfaction with support and need for support. The difference between the two groups in terms of the number of types of support received was statistically significant ( $p < 0.05$ ,  $d o f 29$ ). In terms of supporting the hypothesis that Parents would have greater Social Support than Partners, the results concerning the number of types of support and satisfaction with support were congruent with the hypothesis. Parents greater need for support, along with Partners having greater average number of people providing support are both opposite to the hypothesis.

In terms of the number of people providing each type of support, Parents had a greater average number than Partners on two identified types of support, namely Private Feelings and Material Aid. On the remaining four items Partners had on average more people providing support than Parents.

Thus there is very limited support for the hypothesis that Parents have quantitatively more Social Support than Partners.

In terms of qualitative differences, the rank order of both the types of support received and the sources of support were examined. When the data in Tables 27 and 30 concerning the rank order of the six types of support is considered, it can be seen that there was only one difference in rank order between the two groups.

There was little overall difference in the sources of support for the two groups. When Tables 29 and 32 are examined it can be seen that they shared most of the same sources, and while there were some differences in the rank order of several items, this does not constitute a major difference between the two groups.

Overall, therefore, it can be seen that there is little support for the hypothesis that there are qualitative differences in the Social Support between the two groups with regard to the types and sources of support.

## Health Problems

### Introduction

The Health Problems experienced by the participants in the present study were examined briefly. The hypotheses concerning Health Problems in the present study were as follows:

1. That Partners will experience quantitatively more Health Problems than Parents.
2. That there will be a positive correlation between Stress and Health Problems.

The data from the Health Problems Questionnaire (HPQ) was analysed in terms of the participants as a whole, Parents and Partners separately, and a comparison between the Parents and Partners groups.

Within these three main areas, the HPQ data was examined in the following ways:

1. The overall average HPQ score was calculated.
2. The percentage of each group indicating the presence of each Health Problem was determined.

The HPQ data generated five indices of Health Problems which focus on changes in health status from before the head injury to after. These indices are as follows:

1. Change in an existing condition.
2. The existence of a new condition or problem.
3. Change in the frequency of going to the doctor.
4. An increase in health problems that the doctor is not consulted for.
5. Change in medication, in either quantity or type.

These indices were measured on a 'Yes/No' scale, based on the occurrence or non-occurrence of each type of problem.

## Results

### Parents and Partners Groups Combined

The overall average HPQ score was calculated for the Parents and Partners groups combined as being 1.18. This is quite low on the scale of 1 to 2, and provides limited support for Hypothesis 1.

The percentage of the participants group indicating the presence of each problem is shown in Table 35. These percentages generally indicated low levels of Health Problems.

**Table 35:** Percentage of Parents and Partners combined for whom each Health Problem occurred.

Rank Order	Health Problem	Percentage
1	New problem or condition	32.25%
2	Increase in problems the doctor is not seen for	25.81%
3	Change in medication	16.13%
4	Change in frequency of going to the doctor	12.91%
5	Change in an existing condition	6.45%

The correlation between Stress and Health Problems was 0.6320, and was statistically significant ( $p < 0.001$ ,  $d o f = 29$ ). This supports the second hypothesis, that a positive correlation would be found between these two variables.

### Parents and Partners

#### *Health Problems - Parents*

The Parents group overall average HPQ score was 1.13. The percentage of the Parents group experiencing each Health Problem is presented in

Table 36. The most common problem among Parents was the existence of a new health condition. The numbers of Parents for whom these problems occurred was generally low.

**Table 36: Percentage of the Parents group for whom each Health Problem occurred.**

Rank Order	Health Problem	Percentage
1	New problem or condition	33.33%
2	Increase in problems the doctor is not seen for	22.22%
3=	Change in frequency of going to the doctor	5.55%
3=	Change in medication	5.55%
5	Change in an existing condition	-

A low to moderate positive correlation was found between Stress and Health Problems for the Parents group ( $r = 0.3964$ ,  $d o f = 29$ ). This supports Hypothesis 2.

### *Health Problems - Partners*

An overall average HPQ score of 1.24 was found for the Partners group. The percentage of Partners who experienced each type of Health Problem is presented in Table 37. These results indicate that a degree of Health Problems existed for the Partners group, but not to a great extent.

**Table 37:** Percentage of Partners for whom each Health Problem occurred.

Rank Order	Health Problem	Percentage
1=	Existence of a new condition	30.76%
1=	Increase in problems the doctor is not seen for	30.76%
1=	Change in medication	30.76%
4	Change in frequency of going to the doctor	23.07%
4=	Change in an existing condition	15.38%

The correlation between Stress and Health Problems was high and statistically significant for the Partners group ( $r = 0.8259$ ,  $p < 0.001$ ,  $d.o.f = 29$ ). This supports the hypothesis that Stress and Health Problems would correlate positively.

### Comparison Between Parents and Partners

A comparison was made between the two groups of relatives, to test the hypothesis that Partners experience quantitatively more Health Problems than Parents. One-tailed T tests were performed on the overall HPQ average and the percentages of each group for whom each problem occurred were compared.

Partners had a higher overall average score than Parents, but this difference was non-significant. In terms of the individual item scores, when Tables 36 and 37 are compared, it can be seen that a greater percentage of Partners than Parents experienced four of the five Health Problems. Parents, on the other hand, were more prevalent than Partners on the item concerned with the existence of a new condition or problem.

Overall these results provide support for the hypothesis that Partners experience more Health Problems than Parents, although given the low levels of Health Problems as a whole, the validity of this support is questionable.

## Coping

### Introduction

Data concerning the ways in which respondents cope with stress was collected because of its theoretical relevance to the model of Stress used in the present study, and because it was hypothesised to indicate an aspect of difference between the two groups of respondents. The hypotheses concerned with Coping in the present study were as follows:

1. That Relatives as a whole would use certain Coping strategies more than others.
2. That Parents would use more Problem-focussed coping than Partners and Partners would use more Emotion-focussed coping than Parents.

Three major areas of focus were used in the examination of the Ways of Coping Scale (WCS) data. The Coping strategies used by the Parents and Partners groups combined were examined, as were the Coping strategies used by the Parents and Partners groups separately. A comparison was then made between these two groups.

The WCS data was broken down into the eight subscales identified by Folkman et al (1987), which in turn were collapsed into two major scales - Problem-Focussed Coping (P) and Emotion-Focussed Coping (E). The eight subscales and the major scales to which they belong are listed below:

- |                               |                                 |
|-------------------------------|---------------------------------|
| 1. Confrontive Coping (P)     | 5. Accepting Responsibility (E) |
| 2. Distancing (E)             | 6. Escape-avoidance (E)         |
| 3. Self Controlling (E)       | 7. Planful Problem Solving (P)  |
| 4. Seeking Social Support (P) | 8. Positive Reappraisal (E)     |

These scales have a possible score range of 0 to 3, based on the four-point rating scale used in the administration of the WCS, in which '0' indicated that the strategy in question had not been used, and '3'

indicated that it had been used a great deal.

The WCS data was analysed in the following ways:

1. Average scores were calculated for each of the eight subscales. These were compared between the two groups using a two-tailed T-test.
2. Average scores were calculated for the Problem-focussed and Emotion-focussed scales. These too were compared between the two groups using a two-tailed T test.

## Results

### Parents and Partners Groups Combined

The average scores for each of the eight WCS subscales are presented in Table 38. This data shows that the Coping strategies listed were not widely used by the participants group as a whole, as evidenced by the overall low scores. Of these strategies, Planful Problem Solving was the most commonly used, and Escape-avoidance was used the least. The three Problem-focussed subscales were all quite high in the ranked order of the subscales, indicating that this type of Coping is predominant among the combined Parents and Partners groups.

**Table 38:** Ranked order of WCS Coping strategies as used by Parents and Partners groups combined.

Rank Order	Coping Strategy and Scale	Average
1	Planful Problem Solving (P)	1.17
2	Self Controlling (E)	1.08
3	Seeking Social Support (P)	0.95
4	Confrontive Coping (P)	0.79
5	Distancing (E)	0.76
6	Positive Reappraisal (E)	0.72
7	Accepting Responsibility (E)	0.64
8	Escape-avoidance (E)	0.51

Table 39 reflects the data in Table 38, showing that the Problem-focussed scale had a higher average score than the Emotion-focussed scale. When this difference was examined using a two-tailed T test it was found to be statistically significant ( $p < 0.001$ ,  $d o f = 29$ ). Thus, given that the scores were very low overall it can be seen that in general, a Problem-focussed orientation to coping with stress was used by participants more than Emotion-focussed strategies.

**Table 39: Average scores for Problem-focussed and Emotion-focussed scales for Parents and Partners groups combined.**

Scale	Average
Problem-focussed	0.99
Emotion-focussed	0.76

These results provide some support for the first hypothesis concerned with Coping.

## Parents and Partners

### *Coping Strategies - Parents*

The average WCS subscale scores shown in Table 40 indicated that Planful Problem Solving was the most common strategy used by Parents in the present study. This was followed by the Emotion-focussed strategy of Self Controlling. The least used method of Coping was Escape-avoidance. Problem-focussed strategies were ranked quite highly in this table, indicating that they were more commonly used than Emotion-focussed strategies. Overall, however, the average scores were quite low, which implies that the Coping strategies outlined in the WCS were not used to a great degree by the Parents group.

**Table 40:** Ranked order of WCS Coping strategies as used by the Parents group.

Rank Order	Coping Strategy and Scale	Average
1	Planful Problem Solving (P)	1.35
2	Self Controlling (E)	1.08
3	Seeking Social Support (P)	0.95
4	Confrontive Coping (P)	0.79
5	Distancing (E)	0.76
6	Positive Reappraisal (E)	0.72
7	Accepting Responsibility (E)	0.64
8	Escape-avoidance (E)	0.51

Table 41 shows that Problem-focussed strategies were much more prevalent than Emotion-focussed strategies for the Parents group. The difference between the two types of Coping was found to be statistically significant ( $p < 0.05$ ,  $d o f = 29$ ). This is congruent with the information in Table 40.

**Table 41:** Average scores for Problem-focussed and Emotion-focussed scales for the Parents group.

Scale	Average
Problem-focussed	1.03
Emotion-focussed	0.74

#### *Coping Strategies - Partners*

The average WCS subscale scores for the Partners group were very low on the scale of 0 to 3. Within this, the most commonly used strategies were Planful Problem Solving and Seeking Social Support (both from the Problem-focussed scale), and the least used was Accepting Responsibility. This data is presented in Table 42.

**Table 42:** Ranked order of WCS Coping strategies as used by the Partners group.

Rank Order	Coping Strategy and Scale	Average
1=	Seeking Social Support (P)	0.91
1=	Planful Problem Solving (P)	0.91
3	Self Controlling (E)	0.89
4=	Confrontive Coping (P)	0.82
4=	Distancing (E)	0.82
6	Escape-avoidance (E)	0.73
7	Positive Reappraisal (E)	0.72
8	Accepting Responsibility (E)	0.71

Table 43 indicates that Problem-focussed coping strategies were more prevalent than Emotion-focussed strategies for the Partners group. The difference between the two was statistically significant ( $P = 0.05$ ,  $d o f = 29$ ), although once again these scores are very low overall.

**Table 43:** Average scores for Problem-focussed and Emotion-focussed scales for the Partners group.

Scale	Average
Problem-focussed	0.92
Emotion-focussed	0.77

#### Comparison Between Parents and Partners

When the data in Table 40 and 42 is compared, it can be seen that Parents had higher average scores than Partners on three of the eight subscales. When this is examined in terms of the two major scales - Problem-focussed coping and Emotion-focussed coping, it can be seen that Parents scored higher than Partners on two of the three Problem-focussed subscales and on only one of the Emotion-focussed subscales. This implies that Problem-focussed Coping, while it was more prevalent than Emotion-focussed coping in both groups of respondents, was used more by the Parents group than the Partners group. Correspondingly, Emotion-focussed Coping was more prevalent in the Partners group than the Parents group. None of the differences between the two groups were statistically significant.

The differences between the two groups in terms of the overall Problem-focussed and Emotion-focussed scores are congruent with the above conclusions. Parents scored higher than Partners on the Problem-focussed scale, and Partners higher than Parents on the Emotion-focussed scale. Neither of these differences were significant.

This provides some support for the hypothesis that Parents and Partners used different types of Coping strategies to deal with stress, although these results should be interpreted with caution given the low overall scores for all of the subscales used in this analysis.

## Information

### Introduction

The present study included a number of questions concerning the Information respondents were given at the time of their son/daughter/partners hospitalisation. This data was treated in an exploratory manner, and no hypotheses were proposed in relation to it. The participants group as a whole was examined here, as the issue of information is equally important to all relatives of people with head injury.

This section of the results is divided into three parts, each of which deals with different aspects of the data gathered. The areas examined in the present study were:

1. Whether participants felt that enough information was given to them at the time of hospitalisation.
2. Whether their perception of this adequacy had changed over time.
3. How well the participants understood the information they were given.
4. Whether their understanding had changed over time.
5. General themes and comments from participants.

The types of information referred to in the present study concern the following areas:

1. Their son/daughter/partners condition at the time of hospitalisation.
2. Possible outcomes for their son/daughter/partner.
3. Head injury in general.

Changes in perception and understanding of the information given were assessed by asking about the participants understanding at the time of hospitalisation (T1) and at the time of the interview (T2).

## Results

### Participants Perception of the Adequacy of the Information Given

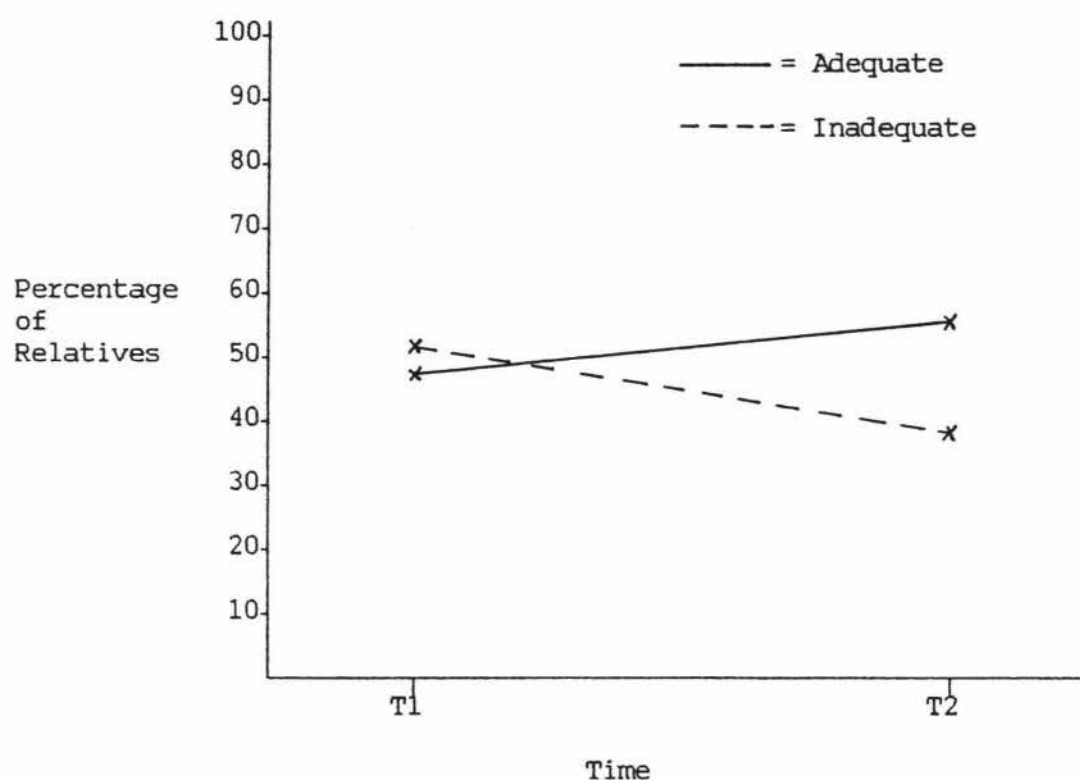
This section is concerned with the first two areas examined in the present study - whether enough information was given at the time of hospitalisation, and whether the Participants' perception of this adequacy had changed over time.

Table 44 shows the percentages of the participants who rated the information given at the time of hospitalisation as adequate or inadequate at both T1 and T2.

**Table 44:** Participants perception of the information received, at the time of hospitalisation (T1) and at the time of interview (T2).

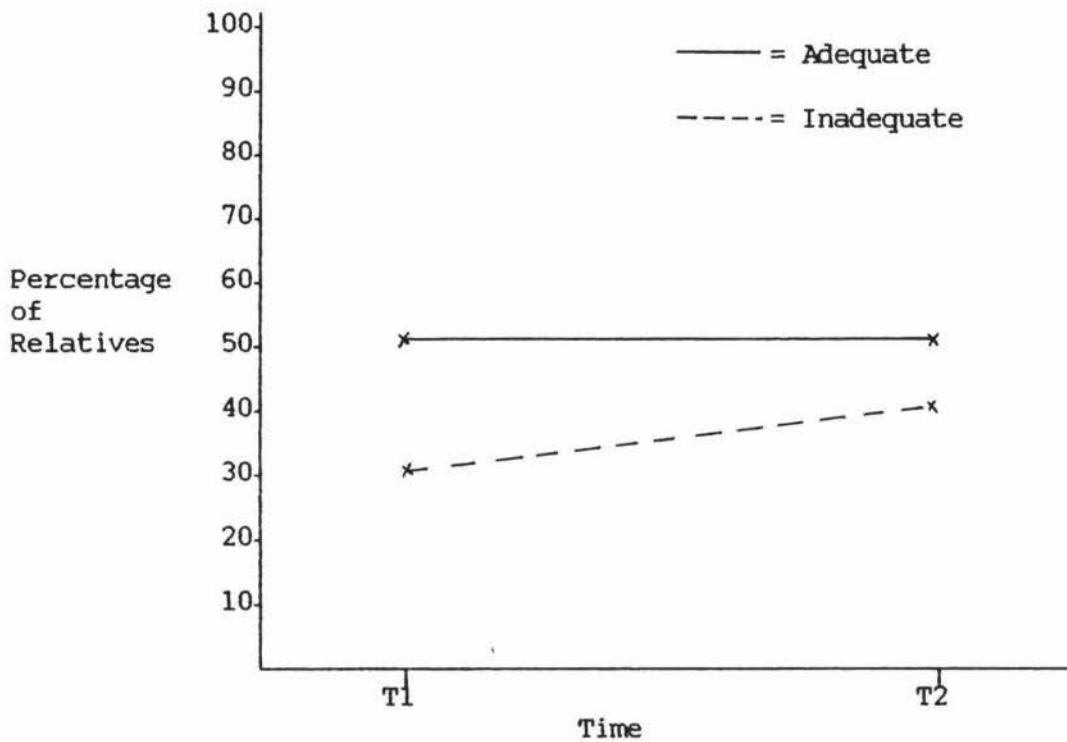
Type of Information	Adequate		Inadequate		N/A	
	T1	T2	T1	T2	T1	T2
Current Condition	48.28%	55.17%	51.72%	37.93%	-	6.89%
Possible Outcomes	31.03%	41.37%	51.72%	51.72%	13.79%	6.89%
Head Injury In General	41.37%	24.13%	51.27%	68.96%	6.89%	6.89%

In terms of information about their son/daughter/partners current condition, at the time of hospitalisation approximately half of the Participants felt the information they were given was adequate, and half felt it was inadequate. By the time of the interview, the number who felt it was adequate had increased to just over half, and the number who felt it was inadequate had decreased to just over one third. These results are summarised in Figure 8.



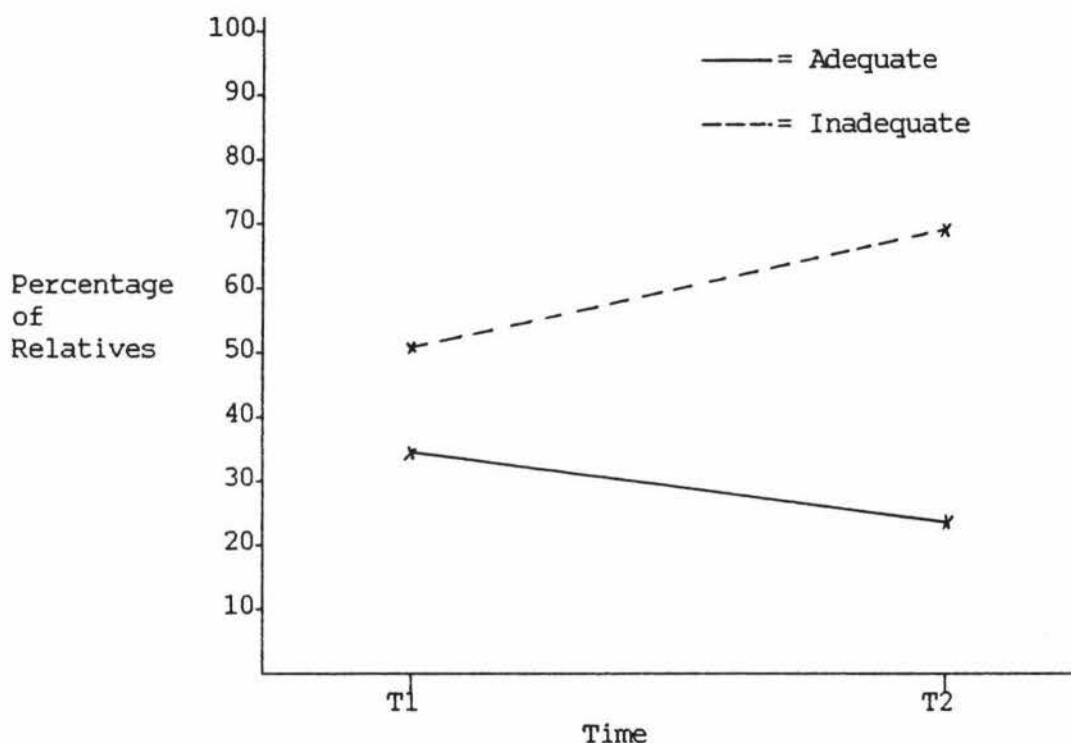
**Figure 8:** Changes in participants perception of the information received concerning their son/daughter/partners current condition.

The information concerning possible outcomes was seen at the time of hospitalisation as being adequate by almost one third of participants, and inadequate by just over 50%. By the time of interview, the proportion considering the information to be adequate had increased to just over 40% of the respondents, while the number seeing it as inadequate remained unchanged. Thus the perceived adequacy of the information about possible outcomes increased slightly over time. This finding is presented in Figure 9.



**Figure 9:** Changes in the participants perception of information received concerning possible outcomes for their son/daughter/partner.

In terms of information about head injury in general, this was perceived at the time of hospitalisation as being adequate by just over 40% of respondents, and inadequate by just over half of respondents. The number of respondents perceiving this information as being adequate at the time of interview decreased to just under a quarter of the group, while the proportion of participants seeing this as inadequate increased to over two thirds. These results are summarised in Figure 10.



**Figure 10:** Changes in participants perception of information received about head injury in general.

In summary, the overall perception of the adequacy of information about current condition increased over time, as did the perception of the information about possible outcomes, although to a lesser degree. The information about head injury in general was perceived as being much less adequate over time.

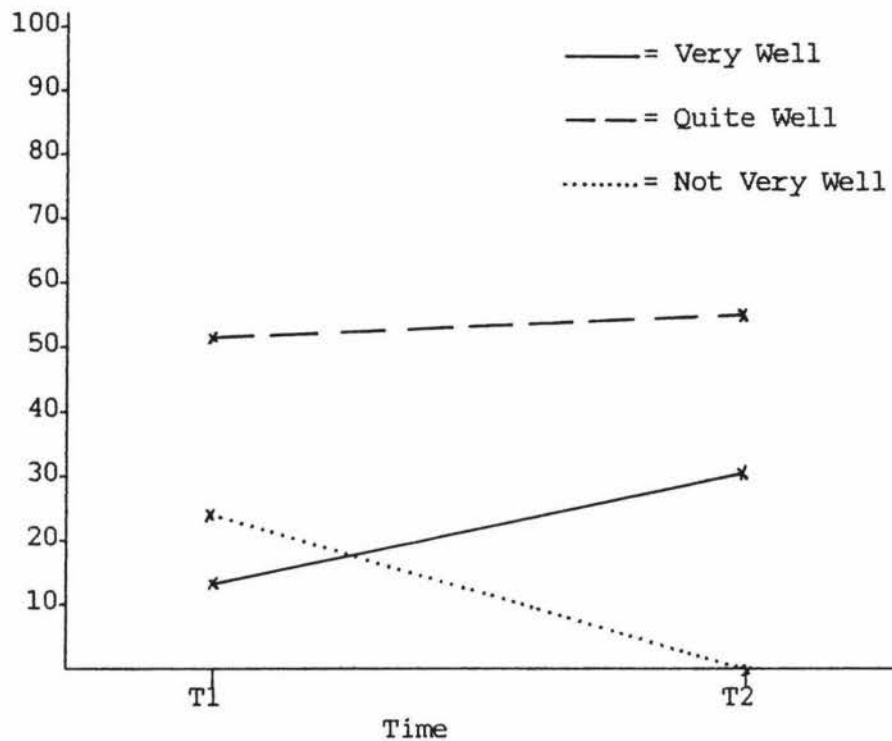
### Participants Understanding of the Information Received

Table 45 shows the respondents understanding of the information they were given at the time of hospitalisation, and changes in this over time.

**Table 45:** Participants understanding of the information given, at the time of hospitalisation and at the time of interview.

Very Well		Quite Well		Not Very Well		Not Relevant	
T1	T2	T1	T2	T1	T2	T1	T2
13.79%	31.03%	51.72%	55.17%	24.13%	-	10.34%	13.79%

Overall it can be seen that the participants understanding of the information they received increased over time. This could be expected, but was not hypothesised. These results are shown further in Figure 11. A number of participants (20.68%) specifically stated that their understanding had increased through their own reading and researching or through experience.



**Figure 11:** Changes in participants understanding of information given.

#### General Themes and Comments

A number of themes and recurring comments were found within the responses to the present study. Firstly, it was noted by a number of participants that the quantity, quality and co-ordination of information (and as noted by some, of care, also) decreases from the Intensive Care Unit to the general hospital wards. One participant noted that information was inadequate until their son/daughter got to the Rehabilitation section of the hospital.

A second theme was the lack of consistency in the availability of information. That is, there was no single, stable, source of information that remained available over time. One participant suggested that New Zealand-based information about head injury should be made available at the Accident and Emergency Department of the

hospital.

Thirdly, many participants indicated that they appreciated that head injury is a very difficult area to give information about. This was however, accompanied by the wish for more information to be available.

Fourthly, a number of participants recognised the difficulty in understanding and/or accepting the information they were given, because they were in a state of shock, and/or didn't want to believe what they were being told. One person said that they expected things to happen the way they do on television, where the person wakes up from a head injury much like waking up from a deep sleep.

These results give some indications of areas of need and possible solutions in terms of the information given to family members of people with head injuries at the time of their hospitalisation.

## CHAPTER SEVEN - DISCUSSION AND CONCLUSIONS

### Introduction

The aim of the present study was to examine the nature of the stress experienced by Parents and Partners of people with head injury. The secondary aim was to look at a number of factors that may contribute to or alleviate this stress. The present chapter will discuss the implications of the results obtained, as well as suggesting possible areas for future research. Discussion of the above issues precede a conclusions section, an overview of some methodological concerns and statistical analysis issues and consideration of implications for service provision.

### Stress

#### Introduction

Two hypotheses were proposed concerning the experience of stress by Parents and Partners of people with head injury. The results obtained for the Parents and Partners groups combined and separately are discussed here with regard to previous research and the hypotheses examined in the present study.

#### Parents and Partners Groups Combined

Previous research indicates that relatives of people with head injuries experience significant levels of stress. The results of the present study are congruent with this, although the levels indicated by the Parents and Partners groups combined were not high. The greatest sources of stress were the areas of family, work and finance. It is difficult to comment on the level of stress indicated in the present study by the participant group because no comparison of stress was made

between the participants and a control group.

The levels of stress that were recorded by the combined Parents and Partners groups may have been related to the severity of the head injuries incurred by their sons/daughters/partners. Although the severity of injury was not measured it could be assumed that they had severe consequences. This assumption is based on the fact that all of the clients had either been referred to the Psychology Clinic for difficulties they were experiencing or had regular contact with their ACC Rehabilitation Co-ordinator, implying high levels of severity of injury. The severity of head injury has been found to be associated with a number of manifestations of stress in relatives (eg Livingston et al, 1985a & b).

The relatively low levels of stress may be attributable to a number of factors. Lezak (1986) suggests that an adaptation process takes place within families of people with head injuries. After approximately 18 to 24 months the family reorganises itself to become physically and/or emotionally disengaged from the head injured person (Lezak, 1986). This may mean that family members adapt over time, possibly in terms of their individual behaviour and also in terms of the overall configuration of the entire family. As a result, what may have once been stressful no longer has this effect. This may, in part, account for the overall low indications of stress within the participants group as a whole. To determine if this scenario were the case, a longitudinal study would need to be carried out, with the aim of examining the adaptation processes within the family and the impact they have on perceived stress.

The low levels of Stress found in the present study may also be attributed in part to the nature of the Stress itself. Peters et al (1990) propose that day to day issues have a high degree of impact on relatives of people with head injury. The present study also focussed on everyday occurrences by examining everyday Hassles. Because the issues measured were small, everyday ones, it may be that when asked,

the participants in the present study did not identify them as being highly stressful because of their unremarkable nature. Thus the apparently low stress levels may be a product of interpretation and reporting factors, rather than the absence of stress itself.

Overall, there is little in the existing literature with which to compare the results of the present study. This is because much of the investigation in this area has focused on the effects of stress on relatives. Thus, studies have used indices such as psychological and psychiatric dysfunction (eg Oddy et al, 1978a; Livingston et al, 1985a & b). This is in contrast to the present study, which sought to examine the nature of the stress experienced by this group.

### **Comparison Between Parents and Partners**

Both Parents and Partners groups showed evidence of experiencing Stress, and both indicated definite sources of Stress. Two hypotheses were suggested concerning differences between Parents and Partners of people with head injury. These concern quantitative and qualitative differences, both of which are discussed separately.

#### **Quantitative Differences**

The present study investigated the hypothesis that Partners would experience quantitatively greater stress than Parents. The results supported this in terms of their direction. Partners had higher overall summary scores and higher average items scores on the DHS than Parents. The difference between the two groups was, however, relatively small and non-significant. Thus, there was partial support for the hypothesis.

The direction of the results obtained is congruent with those of a number of other researchers (eg Blyth, 1981; Panting & Merry, 1974;

Thomsen, 1978). The effects of a family member sustaining a head injury can be expected to impact very differently on Partners and Parents. Both groups can be expected to have special needs peculiar to their relationship with the head injured person.

As suggested by a number of authors, Partners can be expected to experience quantitatively greater stress because of the degree and nature of the changes in their relationship with the head injured person (eg Lezak, 1978; Zeigler, 1987; Thomsen, 1974). When a mutually interdependent relationship changes into one in which one partner has a caregiving/guardianship role with regard to the other, the non-injured person is placed in an unfamiliar role within the relationship. This could leave them very vulnerable to stress. The unfamiliarity of the situation could have a strong impact on their primary appraisals of incidents as being stressful, and their secondary appraisals of their own coping strategies.

Several authors suggest that Parents of people with head injury revert to a familiar parenting role (eg Rosenbaum & Najenson, 1976; Panting & Merry, 1974). It could be suggested that the parent-child relationship is not characterised by the same degree of mutuality as the relationship between partners. Thus an increased reliance on the part of the head injured person does not result in the same degree of unfamiliarity in the parental relationship. It would be more probable that an increase in the degree of parenting would result. While this is suggested to be quite familiar to the people in this position, it is, nevertheless, a stressful position to be in, as evidenced by the Parents group in the present study.

### Qualitative Differences

It was hypothesised that the stress experienced by Parents and Partners would also differ qualitatively. This was supported strongly by the data. Both groups identified different sources of stress. For the

Partners group, primary sources of stress were the home maintenance/household, financial and work areas. The Parents identified family, health and external/environmental issues as being stressful for them.

It was somewhat surprising that the area of the 'relationship with your partner' was not indicated by the Partners group as being a greater source of stress than was reported. Lezak (1978) suggests that the uninjured partners sexual and affectional needs may not be met thus contributing to their stress levels, while Zeigler (1987) focuses on changes in the roles played by each partner in the relationship as a source of stress.

The fact that the Partners group did not, as a whole, indicate that their relationship with their partners was stressful may be explained by the adaptation process suggested by Lezak (1986). The relationship may not be stressful after a period of time because of a combination of the adaptation of the uninjured spouse to the present situation, and gradual changes in the head injured person as part of the natural recovery process. Thus, what was once stressful may be less so in the future.

Lazarus' theory of Stress states that stress is what it is perceived to be, and a relationship that may seem stressful from an observers point of view may not be perceived that way by those involved because they have adapted to the changes that have occurred. Thus, if a person has adapted to changes in their relationship with their partner, they may not perceive the relationship as being stressful.

The social desirability factor, in terms of not publicly acknowledging difficulties within the relationship, may also have had some influence here. Lezak (1978) suggests that guilt about the idea of separation or divorce may also contribute to any down-playing of difficulties within the relationship.

Chamberlain and Zika (1990) noted that qualitative differences in stress could be attributed to the social contexts of different groups. Social context refers to the personal and social situation of an individual (Chamberlain & Zika, 1990) and could be seen to include the relationships people have with others - in this case the nature of the relationship between the participants and their head injured family members.

Within this premise, the areas identified as stressful by both groups reflect their different social contexts. This can be seen in terms of the different types of relationships with the head injured person and the resultant changes therein. The areas of stress identified by the Partners group could be seen to reflect practical changes and areas of difficulty within the relationship. Given the average age and life-cycle position of this group of participants, the effects of the head injury could be seen to emphasise the stress that would ordinarily have been experienced, such as the financial strain that often accompanies having a young family.

The areas of stress identified by Partners could also be suggested to reflect changes in the roles and degree of functioning within those roles that existed in the relationship before the injury. Thus, the uninjured partner may feel a greater degree of responsibility in the areas of the home, finance and work than they did previously, making them more vulnerable to stress.

The stress experienced by the Parents group may reflect an increase in their parenting role, especially in terms of their high level of concern for family issues. Age and position in the life cycle may also have contributed to the Parents concern with their health. This is speculative, however, as demographic information was not included in the analysis. Some literature states that a common concern for parents in this position is that of 'what will happen to their head injured son/daughter when we die' (eg Weddell et al, 1980). Although this was not specifically stated by many of the participants in this group, it

could be seen as a combination of concern for their health and family matters.

Again, there are few grounds on which the results of the present study can be compared with other head injury research. Much of the investigation into qualitative differences between Parents and Partners has focussed on patterns of psychiatric stress and perceived burden (eg Livingston et al, 1985a & b), rather than the actual sources of Stress.

In summary, the present study provided support for both hypotheses concerning the existence of differences between Parents and Partners of people with head injury. Qualitative differences were more apparent than quantitative differences, but both were in evidence.

### Role Change

#### Introduction

Changes in roles experienced by participants as a whole were examined in the present study, as were the differences between the Parents and Partners groups in terms of this variable. The two groups were compared in terms of both quantitative and qualitative differences. The correlation between Stress and Role Change was also examined. These issues are discussed in the following sections. There is little previous literature available to compare the results and conclusions of the present study with in terms of Role Changes.

#### Parents and Partners Groups Combined

The results of the present study lend some support to previous research which has found that relatives of people with head injury experience a degree of Role Change as a result of the effects of head injuries.

The overall degree of Role Change found in the participants as a whole was not large, and was more evident in some areas than in others. The area of greatest change was within the respondents relationship with the head injured person. This could be expected, but was not hypothesised. The next largest area of Role Change was the Social area, which encompassed issues such as going out socially or spending leisure time with the head injured person. The third ranked area of Role Change was within the household, and involved changes in the tasks performed by both the respondent and the head injured person. The area in which the least change was reported was the financial area. It was implicitly expected that changes in the head injured person would be associated with an overall change in roles for the participant, as suggested by Zeigler (1987). This was not the case. Role Changes occurred to a greater degree in some areas than others but was not uniformly present, thereby providing partial support for the initial hypothesis.

Again, the relatively low levels of Role Change indicated by the participants as a whole could possibly be attributed to the adaptation process put forward by Lezak (1986). It could be suggested that, due to the adaptation process, subtle changes in role that occur over time are difficult to identify because they are part of adapting to the new situation. Thus, roles may have changed, but if this change was gradual, it may have been less obvious and not easily reported.

### **Comparison Between Parents and Partners**

#### Quantitative Differences

It was hypothesised that the Partners group would experience quantitatively greater Role Changes than the Parents group. The results obtained provide support for this in terms of an overall summary measure, average individual items scores and average scores for the four general areas of change.

The area in which the greatest difference was observed between the two groups was changes in the financial area. The degree of difference between the two groups was slightly less in terms of the relationship with the head injured person, and decreased again in the household area. The area in which the least difference between the two groups was found was changes in the social area.

Given the suggestion that role changes are greatest between a head injured person and their spouse, it was surprising to note that the difference between the two groups in terms of the role changes in their relationship with the head injured person was not greater than that observed. This would imply that the nature of the relationship between the two groups of respondents in the present study and the head injured family member is not the only important issue within the family after head injury.

As discussed in the section concerned with Stress, the quantitative differences in Role Change experienced by the two groups may be attributed, in part, to their different social contexts. The results show that Partners evidenced a greater degree of Role Change in all areas. These role changes may be related to the unfamiliarity of their present role which, as outlined previously, may now be characterised by less interdependence and more dependence on the uninjured partner by the head injured partner. The lesser degree of Role Change indicated by the Parents group may be due to the fact that they maintain or return to an existing role, in terms of parenting their head injured son/daughter.

The finding that Partners experience quantitatively more Role Change than Parents, especially with regard to their relationship with the head injured person, is consistent with Rosenbaum and Najenson's (1976) results. As suggested by Zeigler (1987), the results obtained here indicate that the relationship between a person with a head injury and their partner is subject to the greatest degree of role change. The partners group indicated greater change in all other identified areas.

It could therefore be suggested that there is an interrelationship between change in the relationship between partners and the changes noted in other areas.

#### Qualitative Differences

The hypothesis that Parents and Partners would have qualitative differences in Role Change was not supported by the results of the present study. Both groups experienced the same patterns of Role Change in terms of individual Role Change items and general areas of change.

This implies that both groups have similar experiences in terms of change in roles. From this it could again be suggested that the relationship with the head injured person is one of many factors that influence the experience of members of both participant groups.

The area in which the least change was experienced by both groups was that of finance. This presents a different result to those obtained in the Stress area, in which finance was one of the greatest sources of stress for the Partners group. This suggests that this was an area of stress regardless of any Role Change associated with it. It also indicates that caution is needed in inferring a causal relationship between Stress and Role Change.

While the quantitative differences between the two groups are congruent with Rosenbaum and Najenson's (1976) results, the lack of qualitative differences in the present study provides no support for their hypothesis that the two groups of relatives have very different experiences within their relationship with the head injured person. Because both groups in the present study had qualitatively similar changes in role, it can be suggested that there are other factors at work apart from the nature of the relationship with the head injured person. These factors may include the severity of the head injury, the

time since injury and whether the head-injured person has returned to their pre-injury activity.

### **Correlation Between Stress and Role Change**

A positive correlation was expected between these two variables. The results provide strong support for this. The correlation between Stress and Role Change was significant for both the participant group as a whole and the Partners group. These results provide support for the idea that a relationship exists between these two constructs. Care must be taken however, not to infer a causal relationship between them.

### **Social Support**

#### **Introduction**

The Social Support data is discussed in a similar way to the previous two sections. The results are discussed as they pertain to the Parents and Partners groups combined, and the differences between Parents and Partners. Quantitative and qualitative differences between Parents and Partners are examined, as is the correlation between Stress and Social Support. Again there is little previous literature with which to compare the results obtained in the present study.

#### **Parents and Partners Groups Combined**

Members of the Parents and Partners groups combined indicated that Social Support of various types was received from various sources. They also indicated high levels of satisfaction with the support they received, and high need for support. The overall satisfaction with support was greater than the overall need for support, which implies that in general the participants need for support was being met.

### Comparison Between Parents and Partners

Both groups indicated receiving support of various kinds from various sources. When the indices of need for and satisfaction with support were compared, it could be seen that the needs of both groups were being met.

### Quantitative Differences

The present study hypothesised that Parents would experience quantitatively more Social Support than Partners. This was based on the assumption that, where there were two parents, both would provide support for each other (Panting & Merry, 1974). The results obtained are inconclusive in relation to this hypothesis. Parents indicated receiving more types of support and a greater degree of satisfaction with the support received. Partners, however, received support from more people, and had less need for support. In addition, Parents received more support in terms of only two of the six identified types of support.

It can be seen that the two groups do not differ to a great degree in terms of the amount of social support they received. It could be concluded therefore, that the amount of Social Support received did not differentiate well between the types of relationship a participant in the present study has with a person with a head injury. This may be because factors such as Social Support are present before the son/daughter/partner becomes head injured and are a function of the Parent or Partner, rather than the head injured person. Therefore Social Support has little association with the type of relationship between the respondents and clients in the present study.

### Qualitative Differences

It was hypothesised that the sources and types of support received by the Parents group would differ from those of the Partners group. This too was based on the hypothesis put forward by Panting and Merry (1974). Overall there was no support for this suggestion. There were no significant differences in the types of support received, and both groups shared most of the same sources of support. Thus, the idea that Parents would be a source of support for each other, but Partners would not receive this support from their head injured partner (Panting & Merry, 1974) was not found in the results of the present study. Members of both groups indicated that their spouse/partner provided them with support, and this was present to a similar degree in both groups.

Rosenbaum and Najenson's (1976) suggestion regarding the presence of tension between wives of men with head injury and their parents-in-law was not replicated in the present study. Parents-in-law were identified by members of the Partners group as a source of Social Support, although they did not rank highly.

Again, it can be questioned whether Parents and Partners are actually two groups that can be differentiated, or whether any differences observed are individually rather than group based.

### **Correlation Between Stress and Social Support**

A negative correlation was expected between Stress and all measures of Social Support except need for support, which was expected to be positively correlated. The results obtained from the present study are inconsistent, and provide inconclusive support for this hypothesis.

Support for the hypothesis was found in terms of the correlation between Stress and need for support in participants as a whole. The

correlation between Stress and satisfaction with support and Stress and need for support in the Parents group also supported the hypothesis. This result was also found in the correlation between Stress and the number of people providing support and Stress and the number of types of support provided for the Partners group.

This could indicate that some differences do exist between the two groups of participants. It could also suggest that the relationship between Stress and Social Support is not a straightforward one. DeLongis et al (1988) found that Social Support was a moderator of the relationship between Hassles and physical and psychological symptoms. Further research, in the form of a multivariate analysis is needed to clarify this matter.

### Health Problems

Health Problems in the participant group were examined in terms of their overall presence, differences between the two groups and the correlation between Stress and Health Problems.

### **Parents and Partners Groups Combined**

Previous literature has indicated quite marked levels of Health Problems in relatives of people with head injury. The results obtained in the present study for the Parents and Partners groups combined provide only limited support for these previous findings. The maximum percentage of the participant group indicating the presence of any of the indices of Health Problems was just under one third. These results differ from those obtained by Panting and Merry (1984), in which they found 61% of the relatives of people with head injury needing tranquilisers and sleeping tablets. The results of the present study are more congruent with those of Oddy et al (1978a), in which 25% of relatives reported illnesses.

Thus, Health Problems were present to an extent in the participant group as a whole, but were not widespread within this group.

### **Comparison Between Parents and Partners**

The Parents group showed a similar pattern of Health Problems to the entire participant group. The Partners group indicated a slightly greater presence of Health Problems than the Parents group and the two groups combined.

### **Quantitative Differences**

The hypothesis that Partners would experience quantitatively more Health Problems than Parents was supported in terms of the direction of differences found between the two groups. The small size and non-significance of the difference, however, somewhat limits this support. There is little in the existing literature to compare these results with. Generally research has focused on the existence of health problems in relatives of people with head injury as a whole, without differentiating between different groups of relatives.

### **Correlation Between Stress and Health Problems**

A positive correlation between these two variables was expected, and the data supported this strongly. A higher correlation between these two variables was found for the Partners group than the Parents group. This result runs parallel to the results in terms of Partners experiencing more Stress and more Health Problems than Parents.

## Coping

### Introduction

Coping is an area that seems to be unaddressed in previous research in the area of head injury research. It was examined in the present study because it was hypothesised to be an area of difference between the two groups of participants under study.

### Parents and Partners Groups Combined

It was hypothesised that the combined Parents and Partners groups would use certain Coping strategies more than others. The results showed this to be the case, although in general the scores on the Ways of Coping Scale were very low. This indicated that the strategies examined were not used very much by the participants, meaning that interpretations should be made with caution.

To the degree that any strategies were used, Problem-focussed Coping was the predominant form of Coping in dealing with a stressful incident in relation to the head injured person. Emotion-focussed Coping was used significantly less by the Parents and Partners groups combined. This may be because Problem-focussed strategies involve dealing directly with the source of stress in a practical manner. This has an immediate and apparent effect and serves to reduce stress in an overt manner. Emotion-focussed strategies make the issue seem less stressful and therefore facilitate the use of Problem-focussed strategies. When a participant is dealing with a problem in relation to the head injured person, both strategies are needed to deal effectively with the situation. The use of both types of Coping was in evidence, although to a limited degree. This was found in the average scores for the Ways of Coping Subscales. The range of these score was reasonably small, indicating that the importance of each type of coping was relatively similar.

Whether the participants in the present study differ significantly on this issue from people who are not in this position would need to be investigated.

### **Comparison Between Parents and Partners**

The present study hypothesised that the Coping strategies used by the two groups would differ. Partial support for this hypothesis was found in the results obtained. Both groups had very low scores, so again caution is needed in interpreting these results. Both groups indicated that Problem-focussed Coping was used more than Emotion-focussed Coping. Parents showed, overall, higher Problem-focussed Coping than Partners, while the Partners group used more Emotion-focussed Coping than Parents. However, neither of these differences was significant.

It could be suggested that Parents may use more Problem-focussed strategies because of their greater maturity and life experience compared to the Partners group. The Partners group may tend to use more Emotion-focussed strategies because of the nature of their relationship with the head injured person. Living with a head injured person in a marital-type relationship may prompt members of the Partners group to avoid or deny issues that may be potential sources of conflict within the relationship, whereas Parents may not feel there is as much at risk in dealing directly with the issue at hand.

Emotion-focussed coping has been found to be used more frequently in situations that are appraised as unchangeable (Folkman & Lazarus, 1980, cited in Folkman & Lazarus, 1985; Folkman et al, 1986). This may have direct relevance to the experiences of Partners of people with head injury. Many aspects of their relationship with the head injured person, and of the head injured person themselves, may be appraised as being unchangeable. This combined with Lezak's (1978) suggestions as to why a non-injured partner may find it difficult to leave such a relationship may prompt greater use of Emotion-focussed coping in

Partners of people with head injury. This may also have been noticeable in the present study because the specific stressful incident the participants were asked to recall was one involving the head injured person.

Overall, the differences between the two groups indicates more of a trend than an absolute difference between them. Partial support for the hypothesis of difference in Coping strategies is therefore found in these results.

### Information

An examination of the combined Parents and Partners groups' perception and understanding of the information they were given at the time of hospitalisation was carried out in the present study. No hypotheses were proposed. The results provide some direction in terms of the information needs of people in this position.

It was disturbing to note that, at the time of hospitalisation, consistently more than half of the combined Parents and Partners groups reported that they felt the information they were given was inadequate. This figure only decreased over time with regard to information about their son/daughter/partners current condition. The other two areas of information increased in adequacy only (ie the inadequacy did not decrease), and decreased in adequacy over time respectively. That is to say, the provision of information about the head injured person's prognosis and head injury in general was inadequate overall. An area of need therefore seems to be the provision of general information about head injury to family members while their family member is still in hospital, especially in the absence of specific information about the family member's condition or prognosis.

In general, as could be expected, participants understanding of the information they were given increased over time. At the time of

hospitalisation, though, only 13.79% understood what they were told very well, and 51.72% understood quite well. This could possibly be attributed to the effects of shock, as noted by a number of respondents. The participants understanding of the information they were given was expected to increase over time because of their constant exposure to the needs of the head injured person and the issues facing them.

Further issues with regard to the informational needs of relatives in general of people with head injury are discussed in the section concerned with implications for service delivery.

### Conclusions

The present study was based on two premises. Firstly that Parents and Partners of people with head injury have certain experiences related to the consequences of head injury. The second premise was that differences in the nature of the relationship between the Parents and Partners and the head injured person would be reflected in differences between the two groups on a number of variables.

The first premise was found to be correct for the combined Parents and Partners groups. A degree of stress and role change was experienced, although health problems were less obvious. Because the experiences of the participant group can be seen to be outside the range of experience of those who are not emotionally close to a person who becomes head injured, the observed stress and role changes could be assumed to be associated with the effects of head injury.

The second premise received partial support. Overall there was a limited degree of quantitative difference between the Parents and Partners groups. Partners indicated a slightly greater degree of stress than Parents. The greatest source of quantitative difference was found terms of Role Changes experienced by Parents and Partners.

There were also some slight differences in the amounts of Social Support received and Health Problems experienced but these were not great.

Marked qualitative differences were found between the two groups in terms of sources of stress, in which Parents identified family, health and environmental issues as stressful and Partners identified financial, household and work issues. This was the most definitive qualitative difference between the two groups. Both experienced similar types of Role Changes and Health Problems. The area of the participants relationship with the head injured person was the greatest area of change for members of both groups. The most common sources of Health Problems for both groups were new health problems and increases in problems the doctor is not consulted about. Both groups had similar sources of Social Support in that their spouse or partner, children and members of their families as a whole were ranked highly by Parents and Partners. Parents and Partners also used similar types of Coping strategies to deal with stress.

Because less difference than expected was found between the two groups, the basic premise underlying this part of the present study should be questioned. This casts doubt on whether Parents and Partners are actually two clearly differentiated groups. The results obtained would seem to indicate that they differ in some ways but overall there is little in the way of group difference between them in terms of their relationship with the head injured person. Some further suggestions for the results of the present study are presented in the section concerned with Statistical Analysis Issues. Further investigation using multivariate analysis techniques to ascertain the relative importance of variables in differentiating between these two groups needs to be carried out if this question is to be answered.

### Methodological Concerns

There are three general areas of methodological concern related to the present study:

1. The actual method used to gather data;
2. General research and self-report issues;
3. A particular concern with the Daily Hassles and Uplifts Scale.

### Methods Used

The Daily Hassles and Uplifts Scale, and the Ways of Coping Scale were administered once to each participant during the course of obtaining the data for the present research. These measures should ideally have had multiple administrations over a period of time in order to give insight into the processes occurring for each participant (Lazarus and Folkman, 1984). However, due to limitations in funding and time and because the focus of the present study was not the process involved, these measures were administered only once. This may have served to distance the results from their theoretical base, thereby limiting their utility. The results obtained therefore act in much the same way as those gathered using many other single-measure research tools.

However, the use of these questionnaires is justified in that their basis in everyday events was very relevant to the area of head injury research. According to Peters et al (1990) the practical issues that are confronted on an everyday basis have a great deal of impact on relatives of people with head injuries. The basic theoretical premise that underpins this scale is also extremely relevant. The idea that stress is what it is perceived to be allows each individual to feel that their individual stress is valid and acknowledged. This is important in this area, given that many of the difficulties arising out of head injuries are invisible at first glance. In addition to this, the scales had a high degree of face validity in terms of being

concerned with real everyday events that were easy to identify with.

### **Self-Report Issues**

There are a number of concerns with self-report measures in general, that have been documented by a number of authors including Kidder and Judd (1986) and Bem and Allen (1974, cited in Conrad & Maul, 1981). Several of the measures used in the present study relied heavily on the participants' memory of events over the past month. Human memory is not notably reliable and is influenced by many factors. Feelings and moods at the time of the interview may have influenced participants response sets (Mason, 1987), especially given the possibly sensitive nature of the research topic. Participants may have experienced a degree of depression or denial with regard to the effects of the head injury either on their son/daughter/partner or themselves. Interviewer effects and a bias towards socially desirable responses have also been especially noted in personal interviews (Kidder and Judd, 1986).

### **DHS Response Scale**

The third concern is a minor one, but should be mentioned in this context, as it may have implications for the future use of the Daily Hassles and Uplifts Scale. This scale uses a four-point likert response scale. The 'zero' score is labelled as 'None or N/A'. There is, therefore, no way to discern between the different processes that may be occurring when this response is scored by a participant. That is, an item may be relevant but may not have been stressful over the past month, or may not have been relevant at all. The present structure of this scale does not allow these two different processes to be differentiated. Future researchers using this scale may want to take this into account.

### Statistical Analysis Issues

There are two main issues that need to be explored here:

1. The implications of the small number of subjects used in the present study;
2. Inference in the context of the present study.

#### **Sample Size**

The present study was based on a collection of data from a relatively small number of participants - 31 in total, divided into two groups of 18 and 13. The small number of participants has two main implications for the analysis of the results obtained.

Firstly, it is well known that the larger the number of participants, and therefore scores obtained, the more likely it is that statistically significant results will be found. Thus, with such a small number of participants, it may be that differences and correlations between the variables examined may actually exist, but may be less apparent in the present research.

Secondly, having such a small number of participants precludes the use of multivariate approaches to analysis. Many of the variables used in the present study are probably linked in some way, so the results obtained may contain some confounding. Because of the small sample size, however, it was not possible to use multivariate methods to control for this or to examine these relationships. Therefore, the results of the present study must be interpreted with caution.

#### **Statistical Inference**

Several factors in the present study affect the inferences that can be

made. Firstly, inference necessitates a random sample from which data is gathered. The participants in the present study may not constitute a random sample of the population of parents and partners of people with head injury. All participants were contacted either through the Psychology Clinic at Massey University, or through ACC Rehabilitation Co-ordinators. Without examining this issue too closely, it could be suggested that this group may have experienced different levels and types of stress to those parents and partners who do not have contact with the Psychology Clinic or a Rehabilitation Co-ordinator on a regular basis. That is, the characteristics of the sample used in the present study may have been biased. Therefore the validity of any inferences made would be questionable on this basis.

Secondly, it would be questionable to make sweeping inferences on the basis of results from such a small sample group. Thirdly, the question needs to be asked as to whether two separate, homogeneous populations of parents and partners of people with head injury actually exist, to make any inferences possible. Because of the vast range of individual differences in any group of people thrown together by circumstances beyond their control, it is doubtful as to whether such populations actually exist.

The fourth concern is an extension of the third, namely whether relatives of people with head injuries as a whole constitute a group that differs significantly from the general population. Because no comparisons were made between the participant group and a control group in the present study it is uncertain whether a separate population of relatives of people with head injury exists to make inferences to.

As a result of these questions, inferences to a population are not relevant to the context of the present study. The results and their discussion are, therefore, couched in terms of the participant groups only, with minimal reference to a larger population.

One further point needs to be noted. The focus of this research is

largely exploratory. This means that the direction of the results, rather than their magnitude, is of primary interest in the context of this discussion.

### Future Research

The aim of the present study was to explore a number of areas that were thought to impinge on parents and partners of people with head injury. From this exploration have come a number of tentative suggestions about the experiences of the 31 people who were interviewed, and some directions for future research.

Overall, it can be seen that there is a need for New Zealand-based and oriented research in this area. Research from outside New Zealand, while it is useful, is based on people who live in a different cultural and environmental milieu, and often includes information that is not relevant to the New Zealand setting (such as the results of certain rehabilitation programmes that are not available here). However, the fact remains that there is little in the way of New Zealand research and literature in this area, especially with regard to the effects of head injury on relatives.

All of the variables examined in the present study need to be examined more thoroughly, in their own right. The present study has established that a number of these variables impact on Parents and Partners of people with head injuries, and that relationships exist between a number of the variables. The impact of these variables and their interrelationships need to be examined in a way that allows their nature to be identified. A multivariate approach would be appropriate in undertaking this.

The processes used by these two groups in terms of stress and coping should be identified. This could be achieved by administering the Daily Hassles and Uplifts Scale, and the Ways of Coping Scale

repeatedly over a period of time. This could be of use in comparing the processes used at different times post-injury, and therefore identifying possible risk-factors for relatives.

Because people with head injury who have the support of their families tend to function better within the community, future research in this area needs to focus on identifying factors that can be used to help these families. The ultimate aim should be to enable families to cope better and provide the support that the head injured person needs. Thus, research needs to focus on everyday practical issues. While the value of clinically-based research is recognised, practical assistance to people in this situation is a necessity. Researchers have a duty to use their resources in this endeavour.

### Implications For Service Provision

Because the present study was largely exploratory, and the examination of the Information issue was the most immediately applicable part of this research, most of the suggestions in this section are concerned with the mechanisms for the provision of information.

The results of the present study indicate the need for a consistent source of information and support. This need is evident from the time of admission, through post-acute care in the general hospital wards, to rehabilitation, and following discharge from hospital.

There are a number of roles that could be filled here by a person such as the Headway or Head Injury Society Fieldworker. Possible areas of work that could be covered, as suggested in the present study include:

1. Being a patient and family advocate while the person is in hospital. For example, helping the family to ask the right questions of the medical staff. This is especially important for family members who do not know how the system works and how to get the most from it.

2. Being an ongoing source of information, both regarding head injury itself, and about related issues, such as hospital procedures and the sequence of events within the hospital system, and services available in the community.

3. Working alongside hospital social workers playing an important bridging role. Some respondents said informally that they felt very much cut off and on their own once their partner/son/daughter had left hospital.

It is envisaged that the fieldworker would have sets of information and resources in a number of media (for example written, video, cassette tape) that could be loaned to the family over a period of time. This would allow them to absorb the information at their own pace, and to refer back to it as often as they needed to. This was an important point made by a number of participants. They stated that often they forgot the things they were told because of their own mental state and needed to be able to go back over the information they were given at their own pace. A concrete example of this would be having multiple copies of Gronwall et al's 1990 publication, which is a New Zealand-based resource specifically written for families of people with head injuries.

The fieldworker would need to be, and be seen to be, independent from the hospital system. This would serve two purposes. Firstly, it would act as a reassurance to the families that they have someone who is purely 'on their side' and there to help them. This is seen as being important as a number of participants noted feelings of antagonism towards the hospital system and medical staff. Secondly, it would enable the fieldworker to see very clearly for whom they are working. If they were to be funded by the Area Health Board or the equivalent structure when these are established, they would be bound to serve that structure rather than work solely with and advocate for the families. This would create a potential conflict of interest that is impossible

to resolve.

This suggestion has implications for funding. This role would necessitate more personnel and therefore more funding for salaries and resources. A greater proportion of this could come from the ACC, given that many of the people incurring head injuries do so through accidents. The need for funding effectively limits the practical likelihood of this position being established.

A number of these suggestions could be implemented without the position of fieldworker being established in this format. Resources could be loaned to families, and could be held in and administered by one section of the hospital such as the Rehabilitation Unit, or Social Work section.

Another practical suggestion is the formation of a volunteer network of people who have been in a similar position. This could be co-ordinated by existing fieldworkers or head injury support groups, to provide a degree of ongoing support where it is needed. Obviously the major limitation to this is the amount of stress that such people are under themselves. This needs to be taken into account in determining the degree of involvement a volunteer network could have, along with all the other implications of having volunteers doing support work of this nature. It could be envisaged that the main area of support provided would be in terms of having someone else understand what the family members are experiencing.

The overriding concern must be with the welfare of the families of people with head injuries. Without adequate and ongoing support, families cannot in turn provide support for the head injured person. As is seen presently, this has serious consequences in terms of quality of life for the head injured person and their family, in addition to the financial costs of crisis intervention and professional input after the event. Preventative assistance must be one of the areas of focus in head injury service provision.

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## APPENDIX ONE: CONSENT FORMS

RESEARCH STUDY ON PERCEIVED STRESS IN PARENTS  
AND PARTNERS OF PEOPLE WITH HEAD INJURY

CONSENT FORM

I, \_\_\_\_\_, have had explained to me the nature of the above research study. I have had the opportunity to ask questions, and these have been answered to my satisfaction.

I consent to take part in the study on the basis of the information provided. I understand that I am under no obligation to continue with the study if I wish to withdraw.

Participant Name:

Signature:

Date:

If you would like to receive information on the results of the study, please leave your address in the space below.

RESEARCH STUDY ON PERCEIVED STRESS IN PARENTS  
AND PARTNERS OF PEOPLE WITH HEAD INJURY

CONSENT FORM

I, \_\_\_\_\_, have had explained to me the nature of the above research study. I have had the opportunity to ask questions, and these have been answered to my satisfaction.

I give consent for information to be taken from my records held at the Psychology Clinic, Massey University, and to be used in this research study. I also give consent for my parent/partner/spouse to take part in the study on the basis of the information supplied.

Client Name:

Signature:

Date:

If you would like to receive information on results of the study, please leave your address in the space below:

**APPENDIX TWO: INSTRUMENTS USED IN THE PRESENT STUDY**

Here is a list of some things that can be considered hassles and uplifts in day to day life. During the course of the last month some of these things will have been only a hassle for you and some will have been only an uplift. Others will have been both a hassle and an uplift. Please think how much of a hassle and how much of an uplift each of these things was for you during the last month. Indicate on the left-hand side of the page (under "HASSLES") how much of a hassle each statement was by circling the appropriate number. Then indicate on the right-hand side of the page (under "UPLIFTS") how much of an uplift it was for you by circling the appropriate number. Remember, circle one number on the left-hand side of the page and one number on the right-hand side of the page for each item.

# THE HASSLES AND UPLIFTS SCALE

How much of a hassle was  
this item for you this month?

## HASSLES

- 0 = None or not applicable
- 1 = Somewhat
- 2 = Quite a bit
- 3 = A great deal

How much of an uplift was  
this item for you this month?

## UPLIFTS

- 0 = None or not applicable
- 1 = Somewhat
- 2 = Quite a bit
- 3 = A great deal

DIRECTIONS: Please circle one number on the left-hand side  
and one number on the right hand side for each item.

- |         |   |         |
|---------|---|---------|
| 0 1 2 3 | 1. Your children  | 0 1 2 3 |
| 0 1 2 3 | 2. Your parents or parents-in-law   | 0 1 2 3 |
| 0 1 2 3 | 3. Other relative(s)  | 0 1 2 3 |
| 0 1 2 3 | 4. Your spouse/partner  | 0 1 2 3 |
| 0 1 2 3 | 5. Time spent with family   | 0 1 2 3 |
| 0 1 2 3 | 6. Health or wellbeing of a family member   | 0 1 2 3 |
| 0 1 2 3 | 7. Sex  | 0 1 2 3 |
| 0 1 2 3 | 8. Intimacy   | 0 1 2 3 |
| 0 1 2 3 | 9. Family related obligations   | 0 1 2 3 |
| 0 1 2 3 | 10. Your friend(s)  | 0 1 2 3 |
| 0 1 2 3 | 11. Fellow workers  | 0 1 2 3 |
| 0 1 2 3 | 12. Clients, customers, patients, etc   | 0 1 2 3 |
| 0 1 2 3 | 13. Your supervisor or employer   | 0 1 2 3 |
| 0 1 2 3 | 14. The nature of your work   | 0 1 2 3 |
| 0 1 2 3 | 15. Your workload   | 0 1 2 3 |
| 0 1 2 3 | 16. Your job security   | 0 1 2 3 |
| 0 1 2 3 | 17. Meeting deadlines or goals on the job   | 0 1 2 3 |
| 0 1 2 3 | 18. Enough money for necessities (eg, food<br>clothing, housing, health care<br>taxes, insurance) | 0 1 2 3 |
| 0 1 2 3 | 19. Enough money for education  | 0 1 2 3 |

## HASSLES

0 = None or not applicable  
 1 = Somewhat  
 2 = Quite a bit  
 3 = A great deal

## UPLIFTS

0 = None or not applicable  
 1 = Somewhat  
 2 = Quite a bit  
 3 = A great deal

0 1 2 3	20.	Enough money for emergencies	0 1 2 3
0 1 2 3	21.	Enough money for extras (eg, entertainment, recreation, holidays)	0 1 2 3
0 1 2 3	22.	Financial care for someone who doesn't live with you	0 1 2 3
0 1 2 3	23.	Investments	0 1 2 3
0 1 2 3	24.	Your smoking	0 1 2 3
0 1 2 3	25.	Your drinking	0 1 2 3
0 1 2 3	26.	Mood-altering drugs	0 1 2 3
0 1 2 3	27.	Your physical appearance	0 1 2 3
0 1 2 3	28.	Contraception	0 1 2 3
0 1 2 3	29.	Exercise(s)	0 1 2 3
0 1 2 3	30.	Your medical care	0 1 2 3
0 1 2 3	31.	Your health	0 1 2 3
0 1 2 3	32.	Your physical abilities	0 1 2 3
0 1 2 3	33.	The weather	0 1 2 3
0 1 2 3	34.	News events	0 1 2 3
0 1 2 3	35.	Your environment (eg, quality of air, noise level, trees and greenery)	0 1 2 3
0 1 2 3	36.	Political or social issues	0 1 2 3
0 1 2 3	37.	Your neighbourhood (eg, neighbours, the area you live in)	0 1 2 3
0 1 2 3	38.	Conserving (eg, gas, electricity, water, petrol, etc)	0 1 2 3
0 1 2 3	39.	Pets	0 1 2 3
0 1 2 3	40.	Cooking	0 1 2 3

# HASSLES

0 = None or not applicable  
1 = Somewhat  
2 = Quite a bit  
3 = A great deal

# UPLIFTS

0 = None or not applicable  
1 = Somewhat  
2 = Quite a bit  
3 = A great deal

0 1 2 3	41.	Housework	0 1 2 3
0 1 2 3	42.	Home repairs	0 1 2 3
0 1 2 3	43.	Yardwork	0 1 2 3
0 1 2 3	44.	Car maintenance	0 1 2 3
0 1 2 3	45.	Taking care of paperwork (eg, paying bills, filling out forms)	0 1 2 3
0 1 2 3	46.	Home entertainment (eg, TV, music, reading)	0 1 2 3
0 1 2 3	47.	Amount of free time	0 1 2 3
0 1 2 3	48.	Recreation and entertainment outside the home (eg, movies, sport, eating out, walking)	0 1 2 3
0 1 2 3	49.	Eating (at home)	0 1 2 3
0 1 2 3	50.	Church and community organisations	0 1 2 3
0 1 2 3	51.	Legal matters	0 1 2 3
0 1 2 3	52.	Being organised	0 1 2 3
0 1 2 3	53.	Social commitments	0 1 2 3

## Others:

0 1 2 3	_____	0 1 2 3
0 1 2 3	_____	0 1 2 3
0 1 2 3	_____	0 1 2 3

# WAYS OF COPING

Please read each item below and indicate, by circling the appropriate category, to what extent you used it in the situation you have just thought of.

	Not used	Used some- what	Used quite a bit	Used a great deal
1. Just concentrated on what I had to do next - the next step	0	1	2	3
2. I tried to analyze the problem in order to understand it better	0	1	2	3
3. Turned to work or substitute activity to take my mind off things	0	1	2	3
4. I felt that time would make a difference - the only thing to do was to wait	0	1	2	3
5. Bargained or compromised to get something positive from the situation	0	1	2	3
6. I did something I didn't think would work, but at least I was doing something	0	1	2	3
7. Tried to get the person responsible to change his or her mind	0	1	2	3
8. Talked to someone to find out more about the situation	0	1	2	3

		Not used	Used some- what	Used quite a bit	Used a great deal
9.	Criticized or lectured myself	0	1	2	3
10.	Tried not to burn my bridges, but leave things open somewhat	0	1	2	3
11.	Hoped a miracle would happen	0	1	2	3
12.	Went along with fate; sometimes I just have bad luck	0	1	2	3
13.	Went on as if nothing had happened	0	1	2	3
14.	I tried to keep my feelings to myself	0	1	2	3
15.	Looked for the silver lining, so to speak; tried to look on the bright side of things	0	1	2	3
16.	Slept more than usual	0	1	2	3
17.	I expressed anger to the person(s) who caused the problem	0	1	2	3
18.	Accepted sympathy and understanding from someone	0	1	2	3
19.	I told myself things that helped me to feel better	0	1	2	3
20.	I was inspired to do something crea- tive	0	1	2	3

		Not used	Used some- what	Used quite a bit	Used a great deal
21.	Tried to forget the whole thing	0	1	2	3
22.	I got professional help	0	1	2	3
23.	Changed or grew as a person in a good way	0	1	2	3
24.	I waited to see what would happen before doing anything	0	1	2	3
25.	I apologised or did something to make up	0	1	2	3
26.	I made a plan and followed it	0	1	2	3
27.	I accepted the next best thing to what I wanted	0	1	2	3
28.	I let my feelings out somehow	0	1	2	3
29.	Realised I brought the problem on myself	0	1	2	3
30.	I came out of the experience better than I went in	0	1	2	3
31.	Talked to someone who could do something concrete about the problem	0	1	2	3
32.	Got away from it for a while; tried to rest or take a holiday	0	1	2	3

	Not used	Used some- what	Used quite a bit	Used a great deal
33. Tried to make my- self feel better by eating, drinking, smoking, using drugs or medication, etc 0		1	2	3
34. Took a big chance or did something very risky 0		1	2	3
35. I tried not to act too hastily or follow my first hunch 0		1	2	3
36. Found new faith 0		1	2	3
37. Maintained my pride and kept a stiff upper lip 0		1	2	3
38. Rediscovered what was important in life 0		1	2	3
39. Changed something so things would turn out all right 0		1	2	3
40. Avoided being with people in general 0		1	2	3
41. Didn't let it get to me; refused to think too much about it 0		1	2	3
42. I asked a relative or friend I respec- ted for advice 0		1	2	3
43. Kept others from knowing how bad things were 0		1	2	3

		Not used	Used some- what	Used quite a bit	Used a great deal
44.	Made light of the situation; refused to get too serious about it	0	1	2	3
45.	Talked to someone about how I was feeling	0	1	2	3
46.	Stood my ground and fought for what I wanted	0	1	2	3
47.	Took it out on other people	0	1	2	3
48.	Drew on my past experiences; I was in a similar situation before	0	1	2	3
49.	I knew what had to be done, so I doubled my efforts to make things work	0	1	2	3
50.	Refused to believe that it had happened	0	1	2	3
51.	I made a promise to myself that things would be different next time	0	1	2	3
52.	Came up with a couple of different solutions to the problem	0	1	2	3
53.	Accepted it, since nothing could be done	0	1	2	3

		Not used	Used some- what	Used quite a bit	Used a great deal
54.	I tried to keep my feeling from inter- fering with other things too much	0	1	2	3
55.	Wished that I could change what had hap- pened or how I felt	0	1	2	3
56.	I changed something about myself	0	1	2	3
57.	I daydreamed or imagined a better time or place than the one I was in	0	1	2	3
58.	Wished that the situation would go away or somehow be over with	0	1	2	3
59.	Had fantasies or wishes about how things might turn out	0	1	2	3
60.	I prayed	0	1	2	3
61.	I prepared myself for the worst	0	1	2	3
62.	I went over in my mind what I would say or do	0	1	2	3
63.	I thought about how a person I admire would handle this situation and used this as a model	0	1	2	3
64.	I tried to see things from the other person's point of view	0	1	2	3

		Not used	Used some- what	Used quite a bit	Used a great deal
65.	I reminded myself how much worse things could be	0	1	2	3
66.	I jogged or exercised	0	1	2	3
67.	I tried something entirely different from any of the above (please describe below)	0	1	2	3
<hr/>					
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### HEALTH QUESTIONS

1. Has any condition you had before \_\_\_\_\_'s accident/illness worsened since his/her accident/illness?
2. Have you suffered from any new physical or emotional illness or problems since \_\_\_\_\_'s accident/illness?
3. Could you indicate what sort of illnesses you have had?
4. Do you go to the doctor more often for matters concerning your own health since \_\_\_\_\_'s accident/illness?
5. Do you suffer from more illnesses since \_\_\_\_\_'s accident/illness that you don't go to the doctor for?

6. What are they?

7. Do you take any more, or any different medications since  
\_\_\_\_\_ 's accident/illness?

8. What are they?

Ok, that's all on health, is there anything you would like to  
ask about what we've done so far? (answer questions)

## ROLE CHANGE

### 1. Everyday Activities

Can you tell me whether there has been any change, how much change, and how things have changed in the following everyday activities since \_\_\_\_\_'s accident/illness:

Firstly, to do with the household:

a) housework                      Y/N                      How much \_\_\_\_

b) general home maintenance                      Y/N                      How much \_\_\_\_

c) larger repairs around the home                      Y/N                      How much \_\_\_\_

d) childcare                      Y/N                      How much \_\_\_\_

e) overall responsibility for day to day running of the home  
Y/N                      How much \_\_\_\_

- f) are there any areas in which change has occurred that I haven't mentioned here?

Secondly, lets look at the financial area:

- a) has the main money earner changed in your house?

Y/N            How much \_\_\_\_

- b) budgeting            Y/N            How much \_\_\_\_

- c) paying bills            Y/N            How much \_\_\_\_

- d) deciding on spending            Y/N            How much \_\_\_\_

- e) Is there anything else I haven't mentioned?

Thirdly, your social life:

- a) the amount of free time you have alone Y/N  
How much \_\_\_\_
- b) the amount of free time you have with \_\_\_\_\_ Y/N  
How much \_\_\_\_
- c) general social activities Y/N How much \_\_\_\_
- d) anything else I haven't mentioned?

## 2. Relationship Changes

Can you tell me whether your relationship with \_\_\_\_\_ has changed, how much it has changed, and how it has changed since his/her accident/illness in the following areas?

- a) equality in the relationship Y/N How much \_\_\_\_

b) who dominates in various areas Y/N How much \_\_\_\_

c) your sexual relationship (if applicable) Y/N  
How much \_\_\_\_

d) communication between you and \_\_\_\_ Y/N  
How much \_\_\_\_

e) the closeness of your relationship Y/N  
How much \_\_\_\_

f) sharing or co-operation Y/N How much \_\_\_\_

g) how similar your relationship is now to what it was  
before \_\_\_\_\_'s accident      Y/N      How much \_\_\_\_\_

h) the closeness of the whole family      Y/N  
How much \_\_\_\_\_

i) are there any other changes in your relationship that I  
haven't mentioned here that you would like to bring up?

Is there anything you need to ask about what we've done so  
far? (answer any questions)

No Change					A great deal of change	
1	2	3	4	5		

## ARIZONA SOCIAL SUPPORT INTERVIEW SCHEDULE

### A. Private Feelings

1. If you wanted to talk to someone about things that are very personal and private, who would you talk to? Tell me the people that you would talk to about things that are very personal and private. (list people) Is there anyone else that you can think of?

2. During the last month, which of these people did you actually talk to about things that were personal and private? (mark appropriate people listed)

3. During the last month, in comparison to the opportunities you had, would you have liked:

1 = a lot more opportunities to talk to people about your personal and private feelings

2 = a few more opportunities

3 = or was this about right?

(mark chosen option)

4. During the past month, how much do you think you needed people to talk about things that were very personal and private?

1 = not at all

2 = a little bit

3 = quite a bit

(mark chosen option)

**B. Material Aid**

1. Who are the people you know that would lend or give you \$25 or more if you needed it, or would lend or give you something (a physical object) that was valuable? You can include some of the people you described before if they fit this description too, or you can name some other people. (record people listed) Is there anyone else you can think of?

2. During the past month, which of these people actually loaned or gave you some money over \$25 or gave or loaned you some valuable object that you needed?

3. During the past month, in comparison to what you were loaned or given, would you have liked people to have loaned you or to have given you:

1 = a lot more

2 = a little more

3 = or was it about right?

4. During the past month, how much do you think you needed people who could give or lend you things you needed?

1 = not at all

2 = a little bit

3 = quite a bit

C. Advice

1. Who would you go to if a situation came up when you needed some advice? Remember you can describe some of the same people that you mentioned before, or you can describe some new people. (list people) Anyone else?

2. During the past month, which of these people actually gave you some important advice?

3. During the past month, compared to what you received, would you have liked:

1 = a lot more advice

2 = a little more advice

3 = or was it about right?

4. During the past month, how much do you think you needed to get advice?

1 = not at all

2 = a little bit

3 = quite a bit

D. Positive Feedback

1. Who are the people that you could expect to let you know when they like your ideas or the things that you do? These might be people you mentioned before or new people. Anyone else?

2. During the past month, which of these people actually let you know that they liked your ideas or liked the things that you did?

3. During the past month, compared to what you were told, would you have liked people to tell you that they liked your ideas or things that you did:

1 = a lot more often

2 = a little more

3 = or was it about right?

4. During the past month, how much do you think you needed to have people let you know when they liked your ideas or things that you did?

1 = not at all

2 = a little bit

3 = quite a bit.

#### E. Physical Assistance

1. Who are the people that you could call on to give up some of their time and energy to help you take care of something that you needed to do - things like driving you someplace you needed to go, helping you do some work around the house, going to the store for you, and things like that? Remember, you might have listed these people before, or they might be new people. (list people) Anyone else you can think of?

2. During the past month, which of these people actual pitched in to help you do things that you needed some help with?

3. During the past month, compared to the amount of help you received, would you have liked:

1 = a lot more help with things that you needed to do

2 = a little more help

3 = or was this about right?

4. During the past month, how much do you feel you needed people who would pitch in to help you do things?

1 = not at all

2 = a little bit

3 = quite a bit

**F. Social Participation**

1. Who are the people that you get together with to have fun or to relax? These could be new people or ones you listed before.  
(list people) Anyone else?

2. During the past month, which of these people did you actually get together with to have fun or to relax?

3. During the past month, compared to the amount of relaxing you did with others, would you have liked:

1 = a lot more opportunities to get together with people for  
fun and relaxation

2 = a few more

3 = or was it about right?

4. How much do you think that you needed to get together with other people for fun and relaxation during the past month?

1 = not at all

2 = a little bit

3 = quite a bit

Do you have any questions you'd like to ask at the moment?

ANSWER SHEET FOR BIOGRAPHICAL DATA

Section 1: \_\_\_\_\_ and their accident

1. Date of birth
2. Number years secondary education
3. Occupation at time of accident/illness
4. How long ago was their accident/illness
5. How did the accident occur
6. Was \_\_\_\_\_ hospitalised
7. Where were they hospitalised
8. How long for
9. What kinds of injuries did \_\_\_\_\_ sustain in the accident/from the illness
10. Was anyone else involved in the accident
11. Since the accident/illness, has \_\_\_\_\_ tried to return to work - what happened

## Section 2: Information

12. Were you given enough information at the time of hospitalisation about:
- a) \_\_\_\_\_'s current condition
  - b) possible outcomes
  - c) head injury in general
13. When it was given did you understand the information you were given
- a) very well
  - b) quite well
  - c) not very much
  - d) not at all
14. Did you think you had been given enough information at the time
15. How clearly did you see at the time that you had been given information
16. Looking back, do you think enough information was given to you about:
- a) \_\_\_\_\_'s condition
  - b) possible outcomes
  - c) head injury in general

17. Looking back, how well do you understand the information that was given to you then - a) very well
- b) quite well
- c) not very much
- d) not at all
18. Now, when you look back, how clearly do you see that information was given or not given to you
19. Are there any other comments

Section 3: Parent/Partner/Spouse Details

20. Date of birth
21. Number years secondary education
22. Job before accident/illness
23. Relationship to \_\_\_\_\_
24. Current type of relationship (if applicable)
25. Number of children
26. Who was main money earner before \_\_\_\_\_'s accident/illness
27. What was their job

28. Has this changed since \_\_\_\_\_'s accident/illness

29. Respondent's current job

Results Summary Y/N

Clinic Card Given Y/N