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ABSTRACT

Primary caregivers of 8 patients who had suffered severe closed head injury were assessed between 1 and 8 years post injury. The presence of behavioural, emotional, and personality difficulties in these patients, and the effects of these on the caregivers, were recorded. Patients' ages ranged from 16.9 to 21.8 years. The problems they most frequently experienced seemed to reflect concerns specific to this age group. Personality disturbances in the patients were significantly related to mood disturbances in the caregivers, while patients' levels of adjustment were not. Caregiver reactions across time were evaluated to assess whether a family's response to a member's head injury are aptly characterised by Lezak's (1986) developmental stage model. Findings revealed that her stages are inadequate explanatory constructs. Implications for research and practice are discussed.

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And last, but not least, to all those who participated in this study and made it possible.

DECLARATION

I hereby declare that this dissertation is my own work and that it has not been submitted to any other University.

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FAMILY STAGES OF ADJUSTMENT: CAREGIVERS' EXPERIENCES OF SEVERE HEAD INJURY

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Masters by Coursework and Dissertation
in the field of Psychology
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FAMILY STAGES OF ADJUSTMENT: CAREGIVERS' EXPERIENCES OF SEVERE HEAD INJURY

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A dissertation submitted to the Faculty of Arts, University of the Witwatersrand, in partial fulfilment of the requirements for Masters by Coursework and Dissertation in the field of Psychology.

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At either end of the continuum of severity, one can distinguish most clearly whether the psychological alterations occur predominantly as the direct or the indirect consequences of brain damage (Lezak, 1988). In reality, however, most brain-damaged patients are positioned somewhere between these extremes, and it becomes practically impossible to distinguish behavioural and emotional expressions that emanate directly from the injured brain; and those that reflect patients' reactions to their situation (Lezak, 1988).

2.2.3. DYSFUNCTIONAL BEHAVIOURS

The possible dysfunctional behaviours arising from brain damage are numerous. Furthermore, the pattern of lingering deficits is likely to vary among individuals after diffuse brain injury. The improvements seen in some functional areas and the worsening of outcome in other areas reveal the multi-factorial nature of recovery after TBI (Brown & Nell, 1992). Person variables (e.g., sex, age, social, intellectual, and behavioural skills, etc.), injury variables (e.g., duration of coma, PTA, brain swelling, etc.), and environmental variables (e.g., degree of structure and consistency in patient's environment, financial and community resources, etc.) are important when considering the heterogeneity and individual differences among persons with TBI - what Shordone (1990) calls the 'person-injury-environment outcome'.

Changes in cognitive, communicative, emotional, behavioural, social, and motor abilities can be seen in each head-injured patient to some extent (Rosenbaum & Najenson, 1976). The literature on the neuropsychological sequelae to head injury reveals problems with post-traumatic amnesia, sustained attention and concentration, new learning and memory, higher level thinking, mental flexibility, visual-perceptual disturbances and various forms of language difficulties (see Peck & Warren, 1989). Consistent patterns of the most frequently noted

2.2.2. THE NATURE OF DISTURBED PATIENT BEHAVIOUR

Lezak (1988) asserts that the majority of brain-injured patients experience two different kinds of behavioural disturbances: those that are best understood as direct consequences of organic conditions; and those that are indirect consequences of brain damage or secondary reactions to their altered mental status. Although many of the patient's emotional and social difficulties may be a consequence of factors such as coping with diminished or altered cognitive functioning and understanding of brain injury, Shordone (1990) argues that a significant amount of these problems seem to stem from the site and the extent of the brain injury. Tissue destruction and associated metabolic and neurohumoral changes affect accompanying behavioural and emotional changes. For example, Becker (1989) argues that the depression frequently found in head-injured patients is often reversible by treatment with mood elevators that increase the brain's catecholamine levels. Although more research is necessary, it is possible that some patient problems may be due to neurotransmitter deficits rather than to situational reality factors.

In general, as the severity of the organic damage increases, the capacity for self-awareness is decreased (Lezak, 1988). Therefore, patients with severe traumatic injuries are typically only dimly aware of their dysfunctions, if at all. At the other extreme are patients who have sustained little tissue damage, whose potential for self-awareness is virtually intact. This means that many of these mildly impaired patients are acutely conscious of their residual difficulties, like reduced mental efficiency. These changes can be embarrassing, fatiguing, frustrating, or even frightening; and typical responses include anxiety, irritability, depression, or social withdrawal (Lezak, 1988). These psychological factors may complicate recovery after head injury (Shordone, 1990)

2.2.1.5. Evaluation of GCS as a measure of severity

The scale has not only provided a standardized method for describing altered levels of consciousness, thereby gauging deterioration and improvement in the acute stages of TBI, but it can also assist in predicting the ultimate outcome as it has been shown to correlate with severity of injury, prediction of mortality and, to some extent, to the morbidity associated with head injury (Bailey & Gudeman, 1989; Teasdale & Jennett, 1974). Klonoff, Costa, and Snow (1986) found that family and patient reports of social adjustment on the Katz Adjustment Scale - Relative's *form* (Katz & Lyerly, 1963) related directly to the initial GCS measures.

Yet, other factors are important when using unconsciousness duration to asses severity. For example, alterations in GCS scores because of alcohol intoxication are well recognised (Bailey & Gudeman, 1989). It is difficult to determine whether impaired consciousness is due to the head trauma severity or alcoholic stupor (Lezak, 1995). This is important considering the strong association of head injury with alcohol intoxication

Generally, the use of unconsciousness duration as a measure of severity is more appropriate for severe injuries than for mild or moderate damage (D.N. Brooks, 1988). Lezak (1986) asserts that almost all closed head injury victims whose coma duration is longer than a few days suffer irreversible alteration of some socially important aspects of their psychological makeup.

& Wrightson, 1980).

2.2.1.3. Unconsciousness Duration

The duration of unconsciousness can range from a few seconds with no permanent damage to prolonged coma and perhaps death (Jennett, 1983). Injury to the brain stem is responsible for loss of consciousness (Becker, 1989). Although a period of unconsciousness is common after closed head injury and is an important sign of developing intracranial pathology, significant hemispheric pathology can occur without the loss of consciousness (Bailey & Gudeman, 1989).

2.2.1.4. Glasgow Coma Scale (GCS)

A method of standardising the assessment of unconsciousness depth, duration, and recovery is through the use of the Glasgow Coma Scale (Teasdale & Jennett, 1974). It is the additive assessment of three aspects of behaviour - motor response, eye opening and verbal response - with scores ranging from 3 to 15. Head injuries have been divided into three categories of severity based on the GCS score: scores of 13 or more indicate mild head injuries, scores from 9 to 12 indicate moderate injury and scores of 8 or less represent severe injuries. Coma has been defined as occurring with a score of 8 or less in a patient without spontaneous eye opening, motor, or verbal responses (Lezak, 1995). Duration of coma can also be used as an indicator of severity, 0-20 minutes representing mild injury, 20 minutes to 6 hours associated with moderate injury, and a coma duration of greater than 6 hours indicating a severe injury (Lezak, 1995). Coma duration alone has been shown to be a poor predictor of outcome for patients with brief periods of coma (20-30 minutes), but is a good predictor for more severe injuries (see Lezak, 1995).

Studies have attempted to correlate PTA with long-term prognosis, and in some cases an increased period of PTA was correlated with increased post-traumatic symptomatology (Bailey & Gudeman, 1989). For example, in a South African study with mild and moderately injured patients, Jansen (1989) found that PTA duration was associated with aspects of well-being, mood, and personality functioning. For the Profile of Mood States (Shortened version; Shacham, 1982) PTA duration was significantly correlated with the Depression-Dejection and Vigour-Activity factors. For the Bipolar Personality Adjective Scale (Jansen, 1988), PTA duration was significantly correlated with Likes company-Dislikes company and Sensitive-Insensitive. Her findings suggest that a short period of PTA can affect the post injury quality of life in subtle ways.

2.2.1.2. Evaluation of PTA as a measure of severity

Difficulties in defining and estimating the duration of PTA has made its usefulness as a measure of severity questionable in some instances (Lezak, 1995). Gronwall & Wrightson (1980) point out that estimating when memory is continuous, as opposed to intermittent lucid states, can be difficult with confused or aphasic patients. Also, assessment of the duration of PTA frequently relies on patients' or even relatives' reports measured retrospectively. These can often be inaccurate.

D.N. Brooks and McKinlay (1983) and N. Brooks, Campsie, Symington, Beattie and McKinlay (1987) reported that PTA duration did not accurately discriminate between moderately and severely injured patients, suggesting that it may not be adequately sensitive in classifying for research (Lezak, 1995). It was, however, more accurate than coma duration in predicting cognitive status two years post injury (D.N. Brooks et al., 1980 in Lezak, 1995). It is also useful when information regarding the initial injury is incomplete or unavailable (Gronwall

for the patient after hospitalisation. However, with severe head injury, both survival and prognosis may be uncertain and predictions may change (E.R.Miller, 1989), which can be difficult for the family. The relationship between injury severity and the caregiver's outcome is discussed later in section 2.4.2.

Typical measures to assess injury severity are the period of post-traumatic amnesia (PTA), duration of unconsciousness, or Glasgow Coma Scale (GCS) scores (Teasdale & Jennett, 1974). These measures are briefly described in order to clarify what constituted a severe head injury in this study. The predictive value of these measures of severity for both cognitive and social recovery has been questioned, however, since factors such as age and premorbid characteristics also play a role in outcome (Jansen, 1989). When these factors are controlled, more positive results emerge. Oddy (1993) and Dalby and Obrzut (1991) reviewed the literature on head injury in children and adolescents, and concluded that a relationship between GCS score, coma, and/or PTA and cognitive deficits exists.

2.2.1.1. Post-Traumatic Amnesia (PTA)

PTA has been defined as the length of time from injury to the moment when the patient has continuous memory for ongoing events (Bailey & Gudeman, 1989). This amnesic period has been linked to disrupted or impaired hippocampal and temporal lobe function (Jennett, 1983). These brain structures are also likely to be instrumental in the long-term problems with memory experienced by many head-injured patients. A period of PTA up to 1 hour is considered a mild injury, 1 to 24 hours is associated with moderate injury, 1 to 7 days is regarded as a severe injury, while a period of PTA greater than 1 week is linked with a very severe injury.

A discussion of these issues is provided below. First, the emotional, behavioural, and personality changes which typically follow severe head injury will be explored, together with their underlying neurophysical correlates. Second, family reactions to these changes in the patient, and the possible correlates of the burden will be examined. And finally, the discussion will focus on Lezak's (1986) developmental stage model of a family's adaptation to head injury.

2.2 DISTURBANCES IN PATIENTS' FUNCTIONING AND THEIR NEUROLOGICAL CORRELATES

2.2.1. ASSESSING THE SEVERITY OF TRAUMATIC BRAIN INJURY

TBIs can range from mild and sometimes unrecognised injury to very severe damage associated with significant morbidity and mortality (Bailey & Gudeman, 1989). Several different pathological processes are activated from the time of injury, any or all of which can increase brain damage and dysfunction and diminish the degree of functional recovery (J.D. Miller, 1989). According to Jennett and Bond (1975), assessment of brain damage is complicated both by the combination of mental and physical features, and the prolonged time period over which recovery seems to continue. Until the duration of active recovery and its underlying mechanisms have been defined, and reliable recovery curves constructed, it is unclear at what time since injury ultimate outcome should be assessed.

Early assessment of the severity of injury to the brain is important in terms of management and prognosis (Jennett, 1983). Since the family is involved even in the acute phases, it is important to try to predict the patient's outcome in order to prepare the family for caring

CHAPTER TWO - LITERATURE REVIEW

2.1 INTRODUCTION

Besides a few very early studies, real interest in recovery after traumatic brain injury (TBI) began in the 1960s. The neurophysical sequelae were initially the primary focus, until later researchers recognised the importance of emotional, personality, and behavioural changes (Brown & Nell, 1992). Although these latter changes are highlighted in the present study, because they are influenced by the mechanisms, sites, and severity of the injury, the structures involved, and the age at injury, a discussion of these issues is also warranted.

Much of the literature on recovery from head injury has focussed on patients' abilities to return to work. Due to the age group used in the present study, this area was not emphasised. More significantly, the importance of helping patients to readjust to family and social life must be underlined because of the substantial stress experienced by relatives years after the injury. Studies examining family reactions to head injury appeared in the 1970s, and became increasingly important during the 1980s. Researchers have addressed the relative's sense of burden, emotional distress, and impaired psychosocial functioning, and have attempted to identify the major correlates of these functional areas. Patient characteristics, like injury severity and residual deficits, as potential predictors of family functioning, have been focussed on (Campbell et al., 1990). More recently, researchers have begun to explore the process of adaptation within the head-injured family and, as Lezak (1986) has done, to develop models to understand this process.

childlike dependency. Clearly, this abrupt change must have negative effects on family functioning and well-being.

A number of theorists have proposed developmental stage models to conceptualise the family's adaptation to a member's head injury. However, Rape, Bush and Slavin (1992) point out that hypotheses about stages have not been subjected to empirical investigation. This is important if such models are to be more than of heuristic value. Lezak (1986) has proposed a stage model and asserts that family reactions to the sequelae go through 6 stages as their appreciation of the patient's condition and how it affects them evolves. The present study wished to test her hypotheses. To empirically test such stage models is a much needed area of research and has important clinical implications. Wortman and Silver (1989) argue that cultural understandings, clinical lore and theories by prominent writers in the area impact on the assumptions people hold about how one should respond to irrevocable losses (such as that which occurs with the personality alterations following severe head injury). If it is assumed that the family's adaptation process unfolds in a particular way, as Lezak (1986) would suggest, those who do not conform to these expectations may be labelled as reacting abnormally or inappropriately. Furthermore, if empirical research does not support the hypotheses proposed in developmental stage models, rigid adherence to a model such as that of Lezak's (1986) may lead the clinician to implement inappropriate interventions that actually hinder the family's adaptation to a member's head injury (Rape et al., 1992; Wortman & Silver, 1989).

the subjective burden on the family is one of the major sequelae following brain injury although nonspecific results regarding the level and course of difficulties experienced by family members are common (K.M. Hall, Karmark, Stevens, Englander, O'Hare, & Wright, 1994). The present study attempted to gain a clearer understanding of this area in a South African population.

In the South African context relatively little work has been performed on family reactions to head injury. Studies on such a population are essential because of cultural differences in family structure and roles, and differences in the delivery of rehabilitation services (Kreutzer, Gervasio, & Camplair, 1994a). These call into question the extent to which research findings from America or Europe may be applicable to South African populations (Camplair, Kreutzer, & Doherty, 1990).

The incidence of head injury is especially high in young adults (15-25 years), and most researchers have included this age group in their studies. However, Kreutzer, Marwitz, and Kepler (1992) note that little has been done to establish the nature of family outcomes for patients younger than age 17. By choosing individuals who fall in the lower end of this age interval, predominantly adolescents, as the subjects in this study, this need could be addressed; and at the same time, direct comparisons with past studies with age groups older than 17 years would be possible. The life stage of adolescent patients is an important consideration in terms of the stresses likely to be experienced by the relatives. Adolescence is a stage when parents begin to witness the emergence of a fully functioning human being who can fill the various roles and capacities expected of a young adult. In contrast with a family's normal evolution toward the independence of children, head injury can bring a sudden end to these expectations and can place the young person back into a state of (perhaps permanent)

CHAPTER ONE - INTRODUCTION

"Head injury happens to people - most often young people whose limitless dreams and aspirations are shattered and whose families are called on to assume a role the dimensions of which are often beyond comprehension and for which they are not prepared" (B.B. O'Brien, 1987, p.421).

1.1 MOTIVATION FOR THE STUDY

Traumatic head injury is a significant public health problem, being the most common cause of brain damage. With the continual improvements in technology and medical care, more head injured patients are surviving than previously. This results in the relatively new and usually tragic phenomenon of physically fit individuals whose brains have been significantly damaged (Lezak, 1995). It is important then that success with a patient "should be measured less by the fact of survival and more by the quality of survival" (Jennett & Bond, 1975, p.481). Consequently, there has been a shift in focus to the determination of the pattern of neurobehavioural outcome associated with head injury since this is what often describes the subsequent quality of life for the patient (Peek & Warren, 1989).

Head injury is usually sustained in motor vehicle accidents, and the rapid acceleration/deceleration forces typical of such accidents tend to produce behavioural disturbances with accompanying personality changes (Lezak, 1986). The characterological alterations in the injured person typically causes major adjustment problems for the patient's family who do not expect, and are unprepared for, such changes. It has been suggested that

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this study must be questioned, however, as a result of the small number of participants (10 wives of brain-injured men, only 2 of which sustained closed head injury; 6 wives of spinal cord injured men; and 14 wives of non-injured men), who constituted a very specific sample (soldiers wounded in battle). The attempt to obtain homogeneity regarding time since injury was at the expense of the number of available subjects (Rosenbaum & Najenson, 1976).

An indication of changes in family reactions over time was first shown by the longitudinal study by Oddy et al. (1978a). Using the Wakefield Depression Scale (Snaith, Ahmed, Mehta & Hamilton, 1971) as a standardised measure to evaluate the emotional distress reported by relatives, these researchers found that the worst period of stress for relatives tended to be shortly after the injury, with 30% of relatives experiencing depression at 1 month post injury. Depression appeared to level off by the sixth month and no further reduction was found at 12 months, with 25% still depressed at these assessments. Kreutzer et al. (1994a) also found 25% of relatives to be depressed, although this was found at 2 years post injury.

Furthermore, in Oddy et al.'s (1978a) group, 25% reported an illness during the preceding 6 months, with approximately 8% on tranquillisers or antidepressants. This is a noticeable difference to Panting and Merry's 61% and this discrepancy suggests the importance of using a standardised, quantitative assessment methodology. Both the Wakefield Scales and the Katz Adjustment Scale employed by Oddy et al. had been used previously with other populations, allowing direct comparisons with prior and forthcoming research. The use of the Katz Adjustment Scale in the present study facilitated such comparisons.

goals to meet the changing needs of its members (Kaplan, Smith, Grobstein & Fischman, 1973; Koseuilek, McCubbin & McCubbin, 1993; E.R. Miller, 1989; Waaland, 1990). There have been few studies which have examined how families successfully manage and cope with the demands of head injury. Numerous recent researchers (e.g., Koseuilek et al., 1993; Olsen, Russell, & Sprenkle, 1983; Rapo et al., 1992) have argued that a family systems perspective is necessary to understand this adaptation process. Family stress and coping theory, with its focus on the impact of major stressors on the family and family efforts to manage them, has also been suggested as a theoretical base from which to work (Koseuilek, 1994).

2.3.1. FAMILY RESPONSES

Panting and Merry (1972) were among the first to investigate family reactions and revealed the magnitude of post injury family problems. They found that the injury had been a great strain on the family members, nearly two thirds required sleep medication or tranquillisers to facilitate coping. However, comparisons with later studies and support for the validity of their findings are difficult since means and standard deviations for duration of unconsciousness and PTA, patient age, socioeconomic status, and time post injury were not provided. Furthermore, the assessment techniques used had uncertain reliability and validity (Kreutzer et al., 1992).

Rosenbaum and Najenson (1976) examined depression and changes in family life 1 year post injury from the perspective of spouses. Compared to spouses of spinal cord injured and non-injured men, the wives of men with brain injury were significantly more depressed. The various symptoms of depression were closely related to the drastic and disturbing changes in everyday life experienced by the wives of severely brain-injured men. The generalisability of

physical signs, family members typically have difficulty in comprehending the mental, emotional, and personality changes that their relative has undergone after severe head injury. It takes time for the family of the patient to appreciate these alterations.

Family members typically assume the long-term care of the patient who is discharged to the home after maximum progress has been realised in inpatient rehabilitation settings (Kreutzer, Leininger, & Harris 1990a). Thus, the family plays a crucial role in the recovery process (Bergland & Thomas, 1991; E.R. Miller, 1989). Yet, family members lack professional training, and so the combination of physical, behavioural, interpersonal, and cognitive dysfunctions in the patient are likely to seem overwhelming. Furthermore, since the quality of support provided for the patient may be compromised by the family's ability to cope with the prolonged stress (Camplair et al., 1990; Kreutzer, Leininger & Harris, 1990a), the family's responses to head injury are of great importance to rehabilitation professionals. There is, however, insufficient empirically derived information on changes in family functioning after TBI and how this relates to the recovery of the patient (Kreutzer et al., 1994a; Leach, Frank, Bouman, & Farmer, 1994). Kreutzer et al. (1992) point out that "cultural diversity as well as differences in design, assessment methods, injury characteristics, and definitions have contributed to difficulties establishing definitive conclusions (p.771). Such research is important for both practical and theoretical reasons: it can assist the education and training of rehabilitation personnel, enable programmes to better address the family's and patient's concerns, and add to the knowledge of family dynamics and family adaptation to extremely stressful situations (Kreutzer et al., 1994a, 1994b).

Since head injury is likely to disrupt established family patterns, adaptive coping by its members is likely to depend on the family unit's ability to readjust roles, priorities, rules, and

Personality changes make exchange between the patient and friends very difficult (Peck & Warren, 1989). B.B. O'Brien (1987) argues that it is not easy for parents to confront a community with the occasionally angry, offensive, and inappropriate behaviour of a traumatized teenager. Witnessing their injured child's hurt at not being able to join their peers in normal activities can be particularly distressful for parents.

The ability to struggle with such issues of self-identity and intimacy comes with the development of conceptual thought. The effect of brain damage on developing executive functions has rarely been studied in adolescence, although it is well established that substantial changes in the frontal area of the brain occur during adolescence (Lehr & Savage, 1990). Neurologically, the brain appears to be going through significant reorganisation, perhaps its last, to become an efficient, stabilised adult brain. Lehr and Savage (1990) assert that "both changes in the frontal or "executive" part of the brain and the more efficient connections are likely to be related to the emerging ability to sustain logical thought in solving abstract and complex problems" (p.306) and more mature judgement. Disruption of these functions is most difficult for the patient's family.

2.3 FAMILY CONSEQUENCES FOLLOWING TRAUMATIC BRAIN INJURY

Traumatic brain injury has an adverse effect on family functioning and satisfaction. The sudden transformation of the brain-injured person's abilities or personality, which prevents the family and the patient from developing adequate defences, together with the lengthy process of recovery can be particularly burdensome for the family (Kreutzer et al., 1994a). The constellation of immediate and long-term mental dysfunctions are not well understood and perplex and frustrate the family (Jansen & Friedman, 1995). Without any obvious

affecting current abilities but also the capacity to continue to develop and learn. Not only do the severely injured experience an immediate loss of developmental time while in a coma and up to the point of recovery where they are able to begin to learn again (Lehr & Savage, 1990), but the primary effect of a traumatic brain injury may be on the rate and process of learning, rather than on a specific ability. Thus, the cumulative impact of deficits on development may only become visible after many years.

Except in studies of head-injured children there has usually been no restriction on age range and the age distribution has varied widely from one sample to another. As Oddy, Humphrey, and Uttley (1978a) point out, "this lack of comparability between samples is all the more regrettable in view of the well-established finding that recovery from head injury is inversely proportional to age" (p.611). Individuals in the age range of 1 to 19 years often have a better outcome following severe brain injury than adults (Gilles & Clark-Wilson, 1993). Since age can be a predictor of outcome, the present study attempted to be specific in its age distribution.

Although adolescents may have more rapid and complete physical recovery, research (see Bergland & Thomas, 1991; Lehr & Savage, 1990) has suggested that they are not spared the psychological (cognitive, behavioral, emotional), physical, and social sequelae. Family disruptions and difficulties with both the academic and social requisites of school have also been reported. TBI can be detrimental to the adolescent's sense of physical attractiveness, perception of invulnerability, self-confidence, social appropriateness, and cognitive capacities. These difficulties can seriously hinder the progression into adulthood both in terms of career development and the development of intimate relationships. Although the peer group is usually a significant part of an adolescent's life, many head-injured patients have reported diminished or absent social contacts beyond those provided by the immediate family.

since, together with tissue movements, there is also widespread tearing of axons and myelin sheaths following impact (J.D.Miller, 1989). And, according to Giles & Clark-Wilson (1993), it is in the younger patients, particularly those under 18, that diffuse bilateral brain swelling appears to occur most frequently. The age of the patient at the time of injury is therefore an important consideration.

2.2.5. ADOLESCENT OUTCOMES

The number of traumatic brain injuries increases dramatically during adolescence. Adolescents begin to obtain their driver's licences and experimentation with drugs and alcohol combined with driving increases the possibility of serious accidents (Lehr & Savage, 1990). Research delineating concerns and outcomes specific to adolescents is sorely lacking. Such research is important since findings from an adult population may not be applicable to adolescents. Adolescents' experiences are poorly understood and not well documented, and much of the literature is presented anecdotally, often reflecting perceptions of professional staff in rehabilitation or clinical settings (Bergland & Thomas, 1991).

Unlike adult injury, understanding traumatic brain injury in childhood or adolescence requires knowledge of the process of recovery/improvement from the injury, superimposed on the overall process of development - both of which occur simultaneously (Lehr & Savage, 1990; Oddy, 1993; Waaland, 1990). Adolescence is a period of experiential learning which defines the person in terms of personality and dealing with the environment. The ability to confront the normal challenges of development depends on such behavioural mastery of oneself and the environment, as well as physical, cognitive, and language skills; and temperament. Some or all of these areas are affected by traumatic brain injury, not only

understanding the neurobiology of differences in mood and affective disorders and underlines the importance of defining and distinguishing specific emotional changes in relation to their neurological bases (Stuss et al., 1992).

2.2.4.2. Rotational Forces

Another mechanism of head injury involves rotational forces. These result in shear strains of delicate nerve fibres and blood vessels as the brain attempts to glide against the inner surface of the skull (Bailey & Gudeman, 1989; Becker, 1989; Lezak, 1988). The forces tend to be greatest on the parieto-occipital region regardless on the direction of injury (Bailey & Gudeman, 1989). Most forces applied to the head have a lateral rotational element so that there is generally greater damage on one side than the other. However, bilateral damage frequently occurs and this has important implications for outcome (J.D. Miller, 1989). According to Goran & Fabiano (1993), greater catastrophic reactions like anger, depression, or anxiety are associated with injury affecting the left hemisphere. Right hemisphere damage can affect various pragmatic language functions, resulting in problems such as hyperverbosity, tangentiality, difficulties in expression or comprehension of emotion. This is likely to affect interpersonal relationships; while the anosognosia and indifference also associated with right hemisphere damage is likely to hamper participation in rehabilitation (Goran & Fabiano, 1993).

Yet, Lezak (1995) argues that clearly distinguishable focal damage is less likely to be seen with injuries that involve significant momentum on impact, as occurs in moving vehicle accidents, and that bilateral damage without definite evidence of lateralisation is common regardless of the site of impact. Indeed, studies have indicated that individuals in motor vehicle related injuries have a high proportion of diffuse injuries (63%) (see Giles & Clark-Wilson, 1993)

to temporal lobe damage, there may be no evidence of remorse because the capacity for self-criticism mediated by this region is diminished or absent (Stuss et al., 1992).

Frontal lobe pathology typically produces a profound effect on personality, and on social and emotional functioning. This is understandable if one notes that the frontal lobes are positioned as a final collection point for information related to both the external sensory and internal limbic (feeling) world. Knowledge of this cortical region and its subcortical connections is extremely important in understanding individual subjective reactions and external behaviours that might be classified as expressions of personality (Stuss et al., 1992). Since the frontal lobes have a critical role in organisation, integration, and guidance of behaviour, these functions are most likely to be affected by head injury (Lezak, 1986). These deficits tend to involve the programming of complex behaviour such that patients have difficulty with modulating and carrying out activities, intentions, and feelings. Although intellectual performance and well-learned skills are rarely affected, these patients are unable to adapt what they know to deal with everyday demands. An individual with an orbitofrontal injury shows an increase in impulsive, disinhibited, antisocial, inappropriate activities; will exhibit poor judgement and insight with little self-monitoring; and has poor control over his/her emotions (Goran & Fabiano, 1993; Shordone, 1990; Stuss et al., 1992).

The frequent problems in initiation, planning and execution of behaviour may be construed as a lack of motivation but reveal diminished autonomous and self-reliant behaviour (Goran & Fabiano, 1993). This is particularly evident in patients with damage to the frontal convexity area who typically exhibit a pattern of apathy, and patients with frontal medial lesions who produce a akinetic mute state (see Shordone, 1990; Stuss et al., 1992). This contrast in behaviour among patients with damage in different areas of the frontal system is useful for

that exist in these areas.

Coup and contrecoup injuries account for specific and localisable behavioural changes that are associated with closed head injuries (Lezak, 1995). Goran and Fabiano (1993) point out that the residual neuropsychiatric symptoms such as paranoia, delusions, obsessionalism, and affective dyscontrol that have been observed in head-injured patients, may be associated with damage to the temporal lobes and deeper structures which are vulnerable to injury in the rapid acceleration and deceleration trauma of MVAs. This is also true for the frequent observations of memory problems. The temporal lobes not only involve the regions of primary and secondary auditory association areas, but also have connections with visual cortex, limbic structures and orbital frontal cortex. These researchers can therefore explain how numerous sensory, perceptual, and emotional changes are possible following temporal lobe damage.

Studies have reported that many months after the injury, patients with extensive temporal lobe damage will frequently exhibit brief, sudden, or violent outbursts of anger in response to minor provocations, followed by emotional distress and remorse (Sbordone, 1990). Emotional alterations may result from dysregulation of autonomic functions associated with limbic connections (Goran & Fabiano, 1993). Furthermore, as explained by Stuss, Gow and Hetherington (1992), in order to make appropriate emotional and social responses, one must be able to judge emotional situations correctly. The anterior brain regions play a significant role in judgement and decision making with both left and right frontal and temporal regions being involved in the judgement of emotional situations and the selection of appropriate responses. Since the orbitofrontal lobes have a role in deciding the appropriate time, place, and strategy for environmentally elicited anger and are important in maintaining sustained aggression, lesions in this area will result in outbursts of anger to trivial stimuli. As opposed

(MVAs), and these closed head injuries and their consequences which the present study wished to examine.

2.2.4.1. Acceleration/Deceleration Forces

It is well established that sudden acceleration/deceleration forces cause substantial movement of the entire brain both within, and relative to, the cranium following a blow to the head. Injuries that occur adjacent to the area of impact are known as *coup* injuries and are most prominent when the head is struck in a relatively fixed position (Bailey & Gudeman, 1989). When the head is freely moveable, a differential acceleration of the cranium and brain is created which results in additional injuries. The soft brain continues to move forward within the already stationary head and collides with the inner table of the contralateral skull surface. This mechanism produces *contrecoup* injuries with damage at the point opposite to that of impact (Bailey & Gudeman, 1989).

With the brain's mobility in the cranium, its poles sustain the greatest deformation by forcibly impinging on the interior surfaces of the skull: "the frontal poles against the anterior fossa, the temporal tips against the sphenoid bones and, less commonly, the occipital poles against the smoother internal surface of the occipital bone" (J.D. Miller, 1989, p.511). Recent evidence (see Giles & Clark-Wilson, 1993) suggests that contusions are not necessarily more severe with contrecoup injuries since individuals with occipital or frontal injuries typically have the most severe damage in the frontal lobes. Also, post-mortem computerized tomography studies have shown that cerebral contusions are more likely to be in the orbital frontal and inferior temporal areas of the brain rather than randomly distributed (see Shordone, 1990). Bailey and Gudeman (1989) argue that the tendency for injury is greater in the frontotemporal regions because of the relative anatomical restrictions to movement and the irregular skeletal surfaces

selfishness, in which the feelings for others, self-criticism, and the ability to reflect are greatly diminished or absent), (3) behavioural rigidity (characterised by an inability to learn from experience even when the ability to absorb new information may be intact), (4) impaired self-control (characterised by impulsivity, random restlessness, and impatience), and (5) increased dependency (characterised by impaired planning, organisation, and judgement with little, if any, initiative despite talk of action). As a result, severely head-injured patients are often considered immature, self-centred, and unrealistic individuals who lack insight and self-directed motivation, and often speak or behave in a socially inappropriate manner (Prigatano, 1992).

This pattern of deficits is virtually dictated by the mechanisms of the injury (Lezak, 1986). The neuroanatomical and neuropsychological aspects of TBI coincide and the link between them is essential in understanding why an individual with head injury will suffer particular changes in various aspects of her/his functioning. Also, it allows for more accurate predictions about the patient's behavioural and neuropsychological disabilities, and likely psychosocial functioning, to be made (Lezak, 1995).

2.2.4. MECHANISMS AND SITES OF CEREBRAL CONTUSION AND THEIR IMPACT ON BEHAVIOUR

The nature of the injury and the pathophysiologic processes precipitated by the damage to the brain differ in significant ways depending on whether it is a closed head injury (in which the skull remains intact and the brain is not exposed) or an open head injury (in which the skull and the meninges are severed) (Lezak, 1995). Most craniocerebral injuries are from the rapid acceleration and deceleration of the head, particularly in motor vehicle accidents

difficulties for the individual with TBI, as reported by relatives, were found by both McKinlay, D.N. Brooks, Bond, Martinage, and Marshall (1981) and K.M. Hall et al. (1994). Fatigue, slowness, and an increase in angry outbursts in particular, are consistently the most frequently reported difficulties during the first year post injury in both studies. Together, the results from the two studies show a perception of progressively increasing behavioural difficulties. K.M. Hall et al. (1994), with their longer, 2-year study, witnessed the continuation of the pattern with 35% of caregivers complaining of aggressiveness by the end of [illegible], and reporting significantly greater severity of temper outbursts. This is also consistent with N.Brooks, Campsie, Symington, Beattie, and McKinlay (1986) who found that bad temper at 1 and 5 years post injury was a common complaint by relatives, and that threats of violence at 5 years were frequent.

Other problems which increased over time reported by K.M. Hall et al. (1994) include anxiety, self-centeredness, and lack of involvement in leisure activities. Only reports of inappropriate social behaviour decreased over time. Lezak and K.P. O'Brien (1988) reported that the proportion of patients exhibiting difficulty with anxiety, depression, and significant relationships increased during the first 12 to 24 months post injury but, continued improvement was generally seen through the third or fourth year. These researchers suggest that "although patients typically improve most rapidly during the first 6 to 12 months post injury, increased awareness of their altered status may [illegible] accompanied by emotional distress, at least initially" (Lezak & K.P. O'Brien, 1988, p.461).

Lezak (1978) has formulated five categories that define the emotional and behavioural problems of the individual with TBI: (1) emotional change (characterised by apathy, silliness, lability, irritability, or changes in libido), (2) impaired social perceptiveness (characterised by

relatives appear to be reacting to the day-to-day difficulties in living with patients. This seems to supported by N. Brooks et al. (1986) who, when evaluating caregiver burden at 5 years post injury, found that individuals with TBI had persistent problems in emotional, behavioural and subjective spheres. The proportion of families experiencing a high level of subjective burden increased from 25% at 1 year to 56% at 5 years, which was particularly associated with the area of disturbed behaviour. In D.N. Brooks and McKinlay's (1983) study, relatives did not report significantly more problems in the patient across the different assessment points during the first year following injury. These researchers therefore conclude that caregivers are less able to tolerate personality changes over time. Behaviours which are inappropriate and embarrassing can be disruptive to family and social exchanges (Peck & Warren, 1989).

Consistent with the studies by European researchers, Kreutzer et al.'s (1994b) American study provided evidence that the caregivers' reports of patients' neurobehavioural problems was the most important and consistent predictor of burden scores. In contrast, K.M. Hall et al. (1994) found that despite caregivers' reports of increasing behavioural problems in their head-injured relatives, there was no trend toward greater self reported stress over time. Perceived burden remained relatively constant throughout the first year post injury and decreased during the second year.

To explain their findings, these researchers point that the method of measuring caregiver distress may be critical. For example, D.N. Brooks et al. (1979) measured it in terms of experienced distress; while Oddy et al. (1978b) measured level of depression, and found that distress defined in this way did not increase with time but actually decreased initially. Using a measure of perceived stress that relied strongly on the concept of self-efficacy, K.M. Hall et al. argue that perhaps as time proceeds and caregivers learn to cope with the ramifications

In Oddy et al.'s (1978a) study, personality change and the relative's perception of the symptoms arising from the head injury (e.g., poorly controlled behaviour) appeared to influence the level of stress experienced. Analysis of Katz Adjustment Scale scores showed elevations on the Confusion and Verbal Expansiveness scales, and these were positively correlated with relatives' depression levels. About 12% of relatives experienced stress because of the concern for the patient's future - fear of another accident or concern about the degree of eventual recovery. The level of stress was not affected by the severity of the head injury, nor by whether the patient had resumed leisure activities.

McKinlay et al. (1981) interviewed a close relative of 88 severely head-injured adults at 3, 6, and 12 months post injury. They defined changes observed in the patient as "objective" burden, which were broadly divided into categories of physical functioning, language, emotional functioning, dependence, subjective complaints, memory, and disturbed behaviour. The stress experienced by the relative emerging from the "objective" changes was defined as "subjective" burden, and this was assessed by a seven-point scale, ranging from no stress to severe stress. A moderate or unchanging level of subjective burden was reported by relatives over the first year after the injury. Subjective burden was significantly associated with emotional problems (e.g. irritability, anxiety, depression), subjective complaints (e.g., slowness and tiredness), and disturbed behaviour (e.g., socially inappropriate or bizarre behaviour) at all assessments; with the number of memory problems at 3 and 6 months post injury; and with the patient's level of dependency at 6 and 12 months. Language problems and physical disability ratings were not related to burden at any time.

Livingston et al. (1985b) reported that the psychiatric and social difficulties experienced by the relatives is associated with the patients' continuing dysfunction and suggest that the

2.4.3. PATIENTS' EMOTIONAL, BEHAVIOURAL, AND PERSONALITY DISTURBANCES

Interviews with relatives in several early studies reported that families experienced greater distress as a result of the brain-injured person's emotional and behavioural changes rather than the physical or language difficulties. However, there is very little information about the power of patient variables to differentially predict particular family reactions, like depression vs. anxiety (Kreutzer et al., 1994a).

Panting and Merry (1972) found that emotional disturbances in the patient were more stressful than physical disabilities which recovered more rapidly. In two studies by Thomsen (1974, 1984), relatives of severely head-injured patients considered personality changes to present the greatest difficulties in daily living. These changes included irritability, anger outbursts, spontaneity, restlessness, lability, emotional regression, and stubbornness. Although these studies lacked a control group, relied on a relatively small sample (n=49), and did not provide evidence for the validity and reliability of family outcome measures, Thomsen was one of the first to recognise the greater importance of behavioural and personality changes, relative to physical changes, in predicting family distress (Kreutzer et al., 1992; Prigatano, 1992).

Similar findings have subsequently been found by Lezak (1978, 1986, 1988), Lezak and K.P. O'Brien (1988), Oddy et al. (1978a), B.N. Brooks & McKinlay (1983), N. Brooks (1984). Patients can become "dependent, demanding, irresponsible, foolish, ill-mannered, or frankly dangerous" (Lezak, 1978, p.893) and this causes great stress for relatives, particularly the primary caregiver.

injured patients with that of minor head injury relatives at 3 months post injury. The relatives of the severely injured were significantly more anxious but not more depressed than relatives of minor head injury patients. Marital and family unit functioning were significantly worse in the relatives of the severely injured, and these relatives reported significantly greater perceived burden. In a second study, Livingston et al. (1985b) found that measures of injury severity (PTA duration, GCS scores) did not predict the relatives' level of distress once the number of a head-injured person's complaints was considered.

According to McKinlay et al. (1981) and N. Brooks et al. (1986), the relationship between the severity of the patient's injury (as assessed by PTA) and the degree of stress experienced by relatives weakened over time, suggesting that stress in relatives is not a simple reflection of severity of injury. Rather, stress is related to certain types of reported problems in the patient. In affirmation of this view, N. Brooks (1992) and N. Brooks et al. (1986) assert that the more severe the initial injury, the more likely the relative is to report high levels of stress, but this is probably due to the increasing occurrence of adverse behaviour and personality change with more severe injuries. Factors other than severity must become increasingly important as time progresses since the extent to which patient outcome, as assessed by a relative, was related to overall severity of injury (duration of PTA), diminished from the first to fifth year after injury (N. Brooks et al., 1986). N. Brooks et al. (1987) subsequently reported that relatives of the most severely injured patients consistently reported high levels of burden up to 7 years post injury, but that no clear pattern emerged for less severely injured patients.

his/her primary support system.

Despite these suggestions, some studies have failed to find differences in the reactions between spouses and parents. Oddy et al. (1978a) found no difference in the depression experienced by parents as compared to spouses, and that there was even a tendency towards greater depression in parents. However, the small number of spouses (n = 14) involved may have impacted on this result. Yet, Livingston et al. (1985a, 1985b) also found no difference between mothers and wives in terms of their emotional distress or psychosocial functioning.

Brooks (1991) argues that if it is the case that spouses experience greater difficulties than parents, then a study which examines only one family member while not wrong may limit the extent to which the study is generalisable to other members. While his argument is valid, the present study wished to limit itself to investigating a parent's reaction to adolescent head injury which is a particularly under researched area. Due to the age restrictions in the present study, spouses were not involved.

2.4.2. IS INJURY SEVERITY RELATED TO FAMILY STRESS?

Both an association and a lack thereof, between severity of injury and relative's outcome, has been documented. For example, although Oddy et al. (1978a) found that the relative's depression was not associated with the severity of the injury; Brown & Nell (1992) reported that the outcome for family relationships is worst for severe injuries and improves as injury severity decreases.

Livingston et al. (1988a) compared the distress experienced by relatives of severely head-

understood since knowledge of the real and potential sequelae of head injury, and the impacts they can have on the caregivers of the patient, is essential to assess both the patient's and the family's needs (Nelson, 1987).

2.4.1. THE CAREGIVER'S RELATIONSHIP TO THE PATIENT

The effects of head injury on the caregiver varies depending on the relative's relationship to the patient. It has been argued that unique stressors are presented to parents versus spouses of survivors (Lezak, 1988; F.R. Miller, 1989). A number of researchers (K.M. Hall et al., 1994; Lezak, 1988; Panting and Merry, 1972; Thomsen, 1974) have observed that relationships between parents and a head-injured child were better than those between injured patients and their spouses. Furthermore, parents have reported lower levels of negative emotion than spouses. Mauss-Clum and Ryan (1981) found that, in comparison to mothers, a greater number of wives reported negative emotional reactions to neurological impairment. Wives were more likely to report depression, anger, guilt, decreased social contacts and less time for themselves, and financial insecurity. However, this study did not employ statistical tests, there were few people with brain injury, and the differences between wives and mothers may be a result of differences in the patient's age, injury type or severity between the two groups (Camplair et al. 1990; Kreutzer et al., 1994a). Yet, Kreutzer et al. (1994b) also found that spouses were significantly more likely to report elevated depression scores compared to parents.

It has been suggested that spouses' adjustment is often less optimal than parental adjustment because while parent caregivers are resuming a previous role, spouses are assuming new roles. Also, parents are able to share some of the responsibility, while the spouse has lost

kind of assessment at all. The only way to get dependable information about these patients is through an informant. However, relatives' reports of their family members' problems may be biased by their own emotional reactions to the situation. They may attribute post injury behaviour to the injury, or they may show sensitisation where their tolerance of a behaviour decreases over time (Giles & Clark-Wilson, 1993). For this reason, any study which concludes that a particular aspect of change in a patient is a "source" of stress for relatives, when relatives' reports for both patient behaviour and for the relatives' own stress has been used, must be treated with caution (McKinlay et al., 1981). A direct causal link between objective burden and subjective burden should not be assumed because of the possible bias.

2.4 CORRELATES OF FAMILY BURDEN

As a result of the high levels of distress and burden in the family members of head-injured individuals, clinicians and researchers have attempted to specify the major correlates and sources of tension (Camplair et al, 1990). It would seem likely that patient descriptors, such as injury severity or the injured person's residual deficits would be related to caregiver burden (Kreutzer et al., 1994b). However, empirical research has not found consistent patterns of this association and the relationship between patient functioning and the caregiver's status remains uncertain. Possible moderating variables include the caregiver's relationship to the patient, the availability of support and information, the presence of other stressors, the premorbid personality of the patient, the characteristics of the family, and the personality of the caregiver (N. Brooks et al., 1986; Koscuilek et al., 1993; Waaland, 1990; Wortman & Silver, 1989). The extent to which all these factors account for the variability among family member's adaptation to head injury has not been investigated (Rapp et al., 1992). It is important that the specific circumstances which contribute to family distress is

perceptions of outcome, particularly in the area of psychologic functioning. As measured by the Bipolar Personality Adjective Scale (Jansen, 1987), patients reported changes with time on a greater number of items than did the caregivers. They expressed greater unhappiness, less energy, greater rudeness, less creativity, more emotionally lability, more tension, and less attentiveness at 12 months than at 6 months; while caregivers rated patients as becoming unhappier and more distractible for this time period. At six months, caregivers rated their head-injured charges as more reasonable and less confident than the subjects rated themselves. These differences in perception diminished with time, since at 12 months post trauma, no differences were found between the caregivers' and patients' views (Brown & Nell, 1992).

It is important that both the patients' and the relatives' views are assessed, especially with severe head injury in which patients are less likely to be aware of their deficits. According to Lezak (1986), even if the patient is aware of a difference, his/her perceptions of the extent and nature of the change may be inaccurate and unreliable. My study examined both the patients' and the caregivers' perceptions using the Bipolar personality adjective scale, at 12 months or more post injury and results were compared to the Brown and Nell study.

Furthermore, some researchers have questioned the objectivity of using relatives as interview and questionnaire respondents about the patient. There are both advantages and disadvantages. Family members, particularly the primary caregiver, are likely to know the patient best and can provide a close view of the patient's day-to-day activities, including types of behaviour the patient only displays with close relatives (Giles & Clark-Wilson, 1993; Katz & Lyerly, 1963). Katz & Lyerly (1963) also point out that some brain-damaged patients cannot respond reliably to a self-rating inventory or they may be unable to cooperate with this

2.3.4. COMPARING CAREGIVERS' AND PATIENTS' VIEWS

When considering change in the patient and the effects this has on the family, it is important to note whose view of outcome is obtained. D.N. Brooks (1991) reviewed a number of studies which have compared relative's reports of deficits in the head-injured person with the patient's own report of their difficulties. Discrepancies between the two sources of information have frequently been found. Burton and Volpe (1993) used the Social Adjustment Scale to examine the relationship between the report of a caregiver and that of the head-injured person in evaluating changes in specific roles of the injured person. The scale measures functioning in the categories of Work (time lost, impaired performance, feelings of inadequacy), Social and Leisure (decrease in contact with friends, leisure activities, romantic relationships, and increase in reticence, hypersensitivity, loneliness), Extended Family (relationships with parents, siblings, in-laws, children not living at home, with measures of withdrawal, reticence, attachment, guilt, resentment), Marital (sexual problems and impaired communication), Parental (lack of involvement, affection, and impaired communication), and Family Unit (economic inadequacy, guilt, resentment) roles. Both the caregiver and the injured person reported moderate impairment for Work, Parental, and Extended Family role functioning. There was good agreement between the reports of the the patient and the caregiver for Work, Social and Leisure, and Extended Family scales, yet little agreement was seen for the Parental, Family Unit, or the Marital scales (Burton & Volpe, 1993). It is noted that these latter 3 categories concern "roles for which the injured person's decreased ability to perform may result in an increased work load as well as decreased satisfaction for the informant" (Burton & Volpe, 1993, p.36).

Brown and Nell (1992) have also reported inconsistencies between patients' and caregivers'

involvement and disengagement in the family. The researchers suggest that this result may reflect the self-centredness and lack of empathy typically shown by head-injured people, or it may reflect the caregiver's perception that other family members are not attentive to the caregiver's needs. About half of the families also reported difficulties in expressing feelings of love and tenderness. This may be a function of the patient's difficult behaviour and altered personality. However, problems of this study included a heterogeneous sample, which may not be representative of, or generalisable to, other studies; and the normative sample used was not very similar to the subjects in the study.

2.3.3. SIBLING RELATIONSHIPS

Little research has been undertaken to examine the impact that head injury in the family must have on siblings of the patient. Oddy and Humphrey (1980) found that at 12 months post injury, there was some evidence of diminished communication between patients and their siblings, but not between the patient and the parent. They suggest that this may be because of greater willingness on the part of the parents to admit that this form of friction occurs while denying that they are personally involved. However, the possibility exists that sibling relationships are more vulnerable and more likely to deteriorate under this form of stress. Waaland (1990) points out that "parents' time and emotional resources typically are drained by caregiving demands and concerns for the injured child" (p.229). Parents may have regret and guilt concerning the amount of time devoted to the patient to the exclusion of their other children (B.B. O'Brien, 1987). The present study did not examine siblings because of the very large number of families which would be required to see trends. The number of siblings, their age, gender, and birth order are all likely to impact on results.

relationships and in relationships with other family members who live in the home. In a study that examined friction in families 6 months following severe closed head injury, Oddy, Humphrey, and Uttley (1978b) found that the patient's marital or family relationships showed no evidence of increasing friction although many patients were reported as showing personality changes. The researchers suggest that their findings may reflect the stage in the recovery process, in that the family may be able to "rally round" initially but may not be able to sustain this indefinately (p.615). Lezak and K.P. O'Brien's (1988) study seems to support this view in that patients indicated increased disturbance and disruption of social relationships 6 to 12 months post injury.

Using essentially the same sample and methodology as the studies by Oddy et al. (1978a, 1978b), Oddy and Humphrey (1980) investigated family relationships over two years post injury in a severely head-injured sample. At the 12-month follow-up, those patients reported to have suffered adverse personality changes had significantly poorer family relationships than those without personality changes, but only when the patient had at least one sibling living at home. Poor family relationships were also associated with a high number of problems in the patient, especially when a relative's perception was considered. However, despite signs of disruptions at 12 months post injury, family relationships seemed to have settled by the two-year assessment.

Using the Family Assessment Device (FAD), Kreutzer et al. (1994a) found that communication problems were most prevalent, with 74% of families scoring in the unhealthy functioning range. FAD Communication subscale items assess the degree to which family members openly and clearly express their thoughts and feelings. About 60% of family informants reported self-centredness and disinterest among family members, on a subscale designed to tap both over-

A group of researchers from Glasgow conducted a very comprehensive and detailed assessment of caregivers' perceptions of burden, emotional distress, and psychosocial functioning after severe TBI. In one study, Livingston, D.N. Brooks and Bond (1985b) assessed severely head-injured patients and their relative at 3, 6, and 12 months after the injury. The relatives' social functioning was initially good, but declined after 3 months post injury and problems remained for the rest of the year. Relatives did not see the patients improving and thus considered for themselves a high level of burden throughout the year. Relatives also experienced significant and persistent anxiety and depression during the first year following injury. Thirty percent of these relatives had sufficient emotional distress to warrant clinical intervention. Consistent with this European study, an American study also found that one-third of caregivers reported high levels of anxiety during the first year post injury (Kreutzer et al., 1994a).

2.3.2. FRICTION IN RELATIONSHIPS

Burton and Volpe (1993) point out that following head injury, the patient remains part of the same complex network that he/she was involved in before the injury. The impact on this network is considerable, and the interactions between the patient and others must necessarily change. Lezak (1978, 1986, 1988) has found that the characterological alterations secondary to brain injury tend to disrupt normal family interaction patterns and create adjustment problems for the patient's close relatives. Without preparation, family members must undergo an adjustment to a "new" person (Waaland, 1990).

Various groups of British researchers have systematically examined family relationships after TBI. Livingston, Brooks, and Bond (1985a) found that problems developed in marital

Also, Waaland (1990) argues that the final stage of "acceptance" does not appear to represent a uniform outcome. She cites a study (Eden, 1984) in which the stages of a model by Polinko, Barin, Leger, and Bachmen (1985) were empirically validated with a group of parents of severely handicapped children. This model's clinical description of family reactions to childhood injury is strikingly similar to Lezak's (1986) model derived from adult head injury, with the family's initial elation for the survival of the head-injured person changing from expectations for complete recovery to depression and mourning when it is realised that impairment is relatively permanent. It is concluded that acceptance, the ultimate goal, may never be achieved, but should rather "be viewed as a fluid state that family members may reach on differing timelines, or perhaps not at all", depending upon family coping strategies (Waaland, 1990, p.231).

Rapp et al. (1992) and Wortman and Silver (1989) have argued that traditional theories of coping with loss and those developmental stage models of a family's adaptation to head injury, can provide some explanation of how individuals move from initially high levels of distress to resolution of their grief over time. However, individuals who do not fit this pattern are not accounted for. It is asserted that the pervasive belief in recovery from loss has deflected attention away from the possible mechanisms through which loss may produce subsequent and continued physical and mental health problems (Wortman & Silver, 1989). In Lezak's (1986) model, perceptions and expectations of the patient are unlikely to be precise mechanisms to account for continued negative family reactions since they do not fully explain changes in family reactions over time. For example, in her last three stages, family reaction alter without corresponding, explanatory changes in the perceptions and expectations. Evidence for precise mechanisms through which head injury can result in long-term difficulties is essential for theoretical advancement and to guide intervention (Wortman &

injured person. It is assumed that this process of mourning is a necessary, natural, and healthy part of the adaptation or recovery process (Kaplan et al., 1973). Lezak (1986) refers to it as "realistic" and "much needed". Garner (1990) and K.M. Hall et al. (1994) have argued that the family will be unable to accept the new changed person unless they have the opportunity of mourning the loss of the old, and the continued presence of the disabled person has the potential to interfere with family members' attempts to achieve psychological adjustment to the loss that has occurred. Lezak (1986) and others (e.g., E.R. Miller) have argued that the professional treating the family with head injury must reassure its members that the sorrow, anger, and guilt they are experiencing are natural reactions for close relatives of head-injured patients. However, in a discussion on how individuals cope with permanent loss, Wortman and Silver (1989) conclude that the available research challenges the presumption that the absence of this process is ultimately maladaptive. The expectation on the part of clinicians that families should mourn can be counterthcrapeutic.

2.5.1.6. Stage 6: Reorganisation

According to Wortman and Silver (1989), none of the models of coping with irrevocable loss postulate exactly how much time should elapse before recovery from that loss although most view failure to recover as pathological. Lezak's (1986) model is no exception. In the last of her stages, reorganisation, with emotional, and perhaps physical, detachment can provide the family with some emotional liberation to pursue a more meaningful life. This can occur between 18 to 24 months or later. Underlying this stage is an assumption that family members will achieve a state of resolution regarding what happened. Yet, studies suggest that this is not the case (particularly when the event is sudden, as in head injury): individuals can not always provide a satisfactory explanation for the experience (Wortman & Silver, 1989).

2.5.1.4. Stage 4: Depression, Anger, Despair, 'Trapped'

When family members realise that little improvement in the patient is likely, and that they themselves are not responsible for the family's distress, they enter a fourth stage of functioning. They expect little or no change. They realise their expectations have been unrealistically high, and they begin to understand what the future holds (Garner, 1990). According to Lezak, most families ultimately struggle through the emotionally overwhelming transition from the unquestioned assumption that the patient is the same person as before the injury to the recognition of permanent alteration in the patient's personality. Depression, anger, and feeling trapped are common. According to Rape et al. (1992), Lezak's model assumes that particular behavioural and emotional reactions accompany the intellectual realisation of permanent damage in the patient. Empirical research is required to identify these specific reactions.

Lezak (1986) argues that the caregiver can only think realistically about the future, other family members' well-being, and the patient's welfare, once full awareness of the extent and chronicity of the patient's dysfunctions is attained. This can take a year or more of floundering without hope. This suggests that the inability to achieve this level of awareness is very problematic since further adaptation depends on such functioning.

2.5.1.5. Stage 5: Mourning

Once the family accepts that the patient is no longer the same person they loved before the injury, and they expect little or no change in his/her functioning, they can move into the fifth stage of realistic mourning over the lost relationship. This mourning process may be obstructed or prolonged because of negative social attitudes regarding mourning for a living person, a lack of social support for any grieving family, and the continued presence of the

2.5.1.3. Stage 3: Discouragement, Guilt, Depression, 'Going Crazy'

The third stage typically develops towards the last half of the first post injury year as hopes for complete recovery diminish. Caregivers see the patient as self-centred, irritable, irresponsible, and lazy. The existence of self-centredness is understandable, since, following the injury, the patient becomes a central focus of attention from relatives and friends. However, with the passage of time "there may be gradual growth of resentment that the patient is so demanding, without, apparently, giving anything in return" (Garner, 1990, p.123). At this point in time, Lezak asserts that the caregiver typically dreams of recovering the premorbid relationship.

As the family attempts to help the patient resume premorbid activities, problems of social inappropriateness and judgement difficulties become clear to the family. The family becomes disappointed and typically blame themselves for the lack of progress. Feelings oscillate between responsibility toward the patient and feelings of frustration, anger, guilt-ridden depression, and helplessness. They expect the patient could reach a stage of independence if they knew how to help him/her. Research indicates that caregivers show anxiety and depression as they begin to acknowledge the patient's deficits and worry about the future (Livingston et al., 1985a, 1985b). Lezak (1986) also provided some empirical research for her assertion that family members become increasingly sensitive to deficits and personality changes over time. For example, she points to Rosenbaum and Najenson's (1976) finding that 1 year after injury is a particularly difficult period for family members. Hopes for complete recovery diminish as progress in various areas of the patient's functioning slows and is less noticeable than before. Also, D.N. Brooks and McKinlay (1983) reported that family members were more likely to complain of personality changes at 6 months (73%) and at 12 months (75%) than at 3 months (57%) post injury.

return to consciousness, past experience with other kinds of illnesses, and clinician's talk of "recovery" when they actually mean "improvement" all contribute to literal expectations for recovery. Studies have found that families often strongly object to early pessimistic predictions by medical professionals, and react to this information with shock and disbelief (Jousen & Friedman, 1995; Mauss-Clum & Ryan, 1981). The family's belief that the results of an evaluation or prognostic statement is inaccurate and inappropriate, can precipitate distrust of, and anger (often emerging from frustration) toward, professionals (Kreutzer, Zasler, Camplair, & Harris, 1990). Many researchers have brought attention to the concept of denial, that is, an unwillingness or inability to acknowledge the adverse effects of brain injury on either the patient or other family members (Klonoff & Prigatano, 1987; Kreutzer, Zasler, Camplair, & Harris, 1990). Eighty-seven percent of the families studied by Kaplan et al. (1973) denied the reality of the diagnosis and Romano's (1974) study of 13 families of severely head-injured patients also provides evidence for such denial.

2.5.1.2. Stage 2: Bewilderment, Anxiety, Frustration

Family members begin to realise that the patient is different in some way, but the subtlety of frontal lobes signs interlinked with premorbid personality characteristics, make identification of the changes difficult. The family views the patient as uncooperative and believe recovery is possible if the patient would show motivation. The family becomes bewildered and anxious as optimism and energy decrease. It may take 6 months to a year or more for relatives to begin to realise the severity and chronicity of the patient's cognitive, emotional, and/or behavioural difficulties (Lezak & K.P. O'Brien, 1988).

TABLE 1: STAGES IN THE EVOLUTION OF FAMILY REACTIONS TO A BRAIN-DAMAGED MEMBER

STAGE	TIME SINCE HOSPITALISATION	PERCEPTION OF PATIENT	EXPECTATION	FAMILY REACTION
I	Approximately 0-1 to 3 months	A little difficult because of (fatigue, inactivity, weakness, etc.)	Full recovery by one year	Pleased and hopeful
II	1-3 months to 6-9 months	Not co-operating, not motivated, self-centred	Full recovery if he'll try harder	Bewildered, anxious, frustrated
III	6-9 months to 9-24 months	Irresponsible, self-centred, irritable, lazy	Independence if know how to help him	Discouraged, guilty, depressed, "going crazy"
IV	9 months or later: can continue indefinitely	A different, difficult, childlike person	Little or no change	Depressed, angry, despairing, "trapped"
V	15 months or later: usually time-limited	A different, difficult, childlike person	Little or no change	Mourning
VI	18 to 24 months or later	A different, difficult, childlike person	Little or no change	Reorganisation

Note: This table is reprinted from Lezak (1986).

2.5.1.1. Stage 1: Pleasure and Hope

Family members initially experience pleasure and hope at the patient's return home. According to Lezak (1986), the patient's childish and demanding behaviour is attributed to less serious short-term factors, like fatigue or excitement at being home. Family members do not expect the patient's personality to change and initially tend to overlook or downplay the patient's altered behaviour, while anticipating a "full, complete recovery" in a very short period (Peck & Warren, 1989). According to Lezak (1986), the rapid improvement following

at 3 months post injury (Livingston et al., 1985a; McKinlay et al., 1981); as well as in the long-term, as late as 10-15 years after the injury (Thomsen, 1984).

2.3.1. DEVELOPMENTAL STAGE MODELS

In order to conceptualise a family's adaptation to a severe head injury in the family, various researchers have proposed different developmental stage models. Waaland (1990) argues that professionals need to be aware of such "stages" of adjustment, which parallel stages of adjustment to death. However, Rape et al. (1992) review a number of these models and argue that these descriptions of a family's adaptation lack empirical support. Furthermore, these researchers state that conceptual problems in the models prevent them meeting the criteria of legitimate explanatory constructs; they are descriptive at best. The present study focuses on Lezak's (1986) developmental stage model (readers are referred to Rape et al., 1992 reviews of other models) which links "stages of perceptions of the injured persons, family expectations, and coping mechanisms to stages of recovery of the head-injured individual" (Waaland, 1990, p.250).

Lezak (1986) asserts that after head injury, most families undergo a series of similar reactions, although not all families are affected in the same way. She conceptualises this process in terms of six different reaction stages which may overlap, or shift back and forth (See Table 1). A family may take 18-24 months to work through the stages of hope, denial, despair, guilt, remorse and mourning; after which they can begin to reorganise their lives again. Family expectations play an essential role in this process as the family reacts in response to their expectations (Lezak, 1978; 1986). Her stages are described below.

injury (Kreutzer et al., 1993; B.B. O'Brien, 1987). The quality and availability of community rehabilitation services has seriously lagged behind the development of acute rehabilitation and neurosurgical interventions (Kreutzer, Leininger & Harris, 1990, Kreutzer, Zasler, Camplair, & Leininger, 1990) and some families cannot afford these services. The highly sophisticated medical systems that enable patients to survive provide little information on how to rehabilitate them (B.B. O'Brien, 1987).

This is even more evident in South Africa. Unlike the sophisticated and extensive diagnostic and remedial services in developed countries, Brown and Nell (1992) point out that in most of the developing countries, including South Africa, such services are rudimentary or nonexistent. Although "acute care rehabilitation of the head injured, such as speech and occupational therapy, is available in South Africa, a shortage o. these therapists prevents many patients from receiving adequate services" (Brown & Nell, 1992, p.767). In their study, family relationships appear to be the most negatively affected by TBI; yet, "not one of the subjects canvassed had presented for or received supportive psychotherapy or family counselling, which is a reflection of the unavailability of such services in public and private hospitals" (Brown & Nell, 1992, p.767).

2.5 FAMILY ADAPTATION PATTERNS

Recovery after head injury is often characterised by apparent plateaus followed by unexpected progress (Kreutzer, Zasler, Camplair, & Harris, 1990). Stress levels are likely to vary as relatives witness changes in the patient, as new services are offered, or as therapies are terminated (Kreutzer, Zasler, Camplair, & Harris, 1990). There is evidence of substantial family distress and a strong sense of burden both in the very early stages after head injury,

2.4.4.3. A Lack of Professional Help

Findings of long-term family stress following head injury suggest that support for the family is necessary throughout and beyond the first year of injury, not just during the initial stages (Kreutzer, 1992). So that rehabilitation professionals can better understand and respond to the needs of families, accurate information regarding family reactions and functioning is essential. Such information is also necessary to develop programs and services that "facilitates the family's, and therefore the injured person's, adjustment to disability following traumatic brain injury" (Camplair et al., 1990, p.207). Abelson (1987) found that patients who had attended rehabilitation programmes, and/or received devoted attention from their families reached a higher level of recovery than those patients who were not fortunate enough to receive this attention.

Lezak (1986) asserts that counselling family members can improve the quality of their adjustment and their care of the patient. She argues that professionals need to help family members understand the nature and the course of injury, to aid more realistic expectations, and to enable them to work through the conflicts and pain generated by the injury. More consistent and realistic information about behavioural difficulties in TBI and their likely impact on the family should be provided, together with ongoing training in behaviour management and other techniques which can minimise the disruption of family functioning (Kreutzer et al., 1994b).

However, Kreutzer et al. (1994b) assert that despite the allegedly greater availability of co-ordinated rehabilitation programmes in the United States, families of outpatients still reported difficulties. Feelings of frustration, exhaustion, and grief are complicated by a system that does not seem to understand the needs or is ill-equipped to help survivors of severe head

injury seems to be largely determined by the availability of quality support (Waaland, 1990, p.233). Social support is hypothesised to serve as a buffer between stress and health breakdown and can facilitate adaptation to head injury. Poor or low social support may exacerbate stress, which may result in increased failure to cope with stressful events and thus depressive symptoms (Kosciulek et al., 1993; Leach et al., 1994).

As the family of the head-injured patient develops an understanding of the patient's condition, identification and ventilation of feelings about the patient, his situation, and the effects of this situation on family members can be very helpful (B.B. O'Brien, 1987). Networking with other family survivors who have experienced head injury can provide support and guidance. Feelings of isolation, self-pity, and the perception that "no one else could understand" are often reduced as family members are able to disclose their fears, anger, and "unacceptable thoughts" to others who have experienced similar circumstances (B.B. O'Brien, 1987; Waaland, 1990). It may be that only individuals who have experienced caregiver burdens understand the reality of the situation sufficiently to be genuinely supportive (Lezak, 1978).

Support from friends and the extended family is often available at the time of the injury and the few months following, but as time goes on and progress appears to lessen, support frequently decreases and the family members become increasingly isolated. The size of the family's social network decreases, and at the same time, family members serve more and more roles to compensate for lost relationships with non-relatives (Kozloff, 1987). For example, relatives would not only provide financial or practical support but would also serve the patient's social needs. This is very tiring for family members, and both the patient and the caregiver need time away from one another.

2.4.4.1. A Lack of Information

Since families have misconceptions about TBI, there is a strong need for better education of families with a head injury. Erroneous understanding can result in unrealistic expectations (Sbordone, 1996) and the family's expectations for recovery have a profound effect on how the family copes with the stress created by the patient's altered behaviour.

The family's reported need for appropriate information and education is well established. One of the most frequently asked questions is 'What can we expect for our child in the future?' (Waaland, 1990). According to Oddy et al.'s (1978a) study, the relatives' greatest need is for an estimate of the future course of personality changes since this is an important source of stress for caregivers. Jansen and Friedman (1995) found that relatives often did not clearly understand at the time what the implications of the injury would be, and no information was given to any relatives on how to cope with the patient's behaviours. They reported that "the nature of the information given was primarily concerned with ... the physical aspects of recovery. No mention of the cognitive consequences or personality changes that can occur was made. It has been reported that many families of head injury victims do not realise the need for specialised rehabilitation following discharge from hospital beyond restoration of function" (Jansen & Friedman, 1995, p.521). Most families have no frame of reference about head injury and obtaining information can reduce the anxiety about something incomprehensible (B.B. O'Brien, 1987).

2.4.4.2. A Lack of Support

Although education may help the family to adjust, it does not compensate for parent strain created by inadequate community resources. Lack of available respite care also adds to burden, and marital satisfaction, family adjustment, and prognosis for the patient with head

of the injury, they feel more effective although not necessarily less distressed. Although subjectively experienced stress seemed to decrease, the incidence of psychosocial dysfunctioning in caregivers, as manifested through behavioural events like substance use and participation in counselling, increased (K.M. Hall et al., 1994). This is perhaps indirect evidence for increasing distress levels. However, it may have been possible that between 1 and 2 years post injury, caregivers achieved resolution and accommodation as proposed in Lezak's (1986) model of family reactions to TBI.

In order to plan effective management of TBI patients' many behavioural and social problems, the nature and course of personality alterations following TBI must be understood (Lezak & K.P. O'Brien, 1988). It is for this reason that my study focussed on these areas, rather than physical disabilities.

2.4.4. INADEQUATE KNOWLEDGE AND ASSISTANCE

Early studies (e.g., Oddy et al., 1978a; Panting and Merry, 1972; & Thomsen, 1974) found that complaints by relatives of inadequate support and insufficient information regarding prognosis and possible difficulties were common. The lack of long-term care guidelines and appropriate support services results in additional burden on the family attempting the adapt to head injury (Kosciulek et al., 1993, p.43). A recent study in South Africa (Jansen & Friedman, 1995), which examined the acute and post-acute period of hospitalisation, has found that these difficulties still persist for relatives. My study proposed to assess caregivers' experiences of available support systems 1-5 years post injury. With support and assistance, families can become an important resource for care of the head-injured patient (E.R. Miller, 1989).

and frustrations within the family in order to assess communication. In each of these cases, the caregiver was asked to evaluate what effect the family behaviour pattern had on him/her.

From the literature on head injury and on family stress and coping, Kosculick (1994) constructed a set of 30 potential behaviours families may use to cope with head injury. Questions about seeking support, continuing family activities together, and accepting the head-injured member as s/he is without dwelling on the past were selected from this researcher. Kosculick et al. (1993) assert that family time together is critically important and is a relatively reliable indice of family integration. Parkes and Weiss (1983) found that those individuals who yearned constantly for the deceased 3 weeks after the loss, showed poorer outcome 2 to 4 years after the loss than those who yearned never, seldom or only when reminded of the loss. Furthermore, the issue of yearning is very important in terms of Lezak's (1986) stage model. She asserts that the family must accept the patient as different and changed from the injury before they can enter the stage of mourning. A family who has reached the stage of reorganization should be able to accept the patient as different without dwelling of the past. Thus, in addition to assessing family coping behaviours, this question allowed Lezak's assertion to be tested.

If Lezak's (1986) developmental stage model is accurate, then a family 1-5 years post injury should expect little or no change in the patient's functioning, or in some cases they may expect independence if they know how to help. The biographical questionnaire attempts to assess the family's expectations at the present time, as well as their past expectations. This an essential aspect to assess given the importance Lezak attributes to expectations in family reactions. Similarly, because of the status placed on psychological intervention by Lezak (1986), the biographical questionnaire determined what help had been available for these head-injured families, and what help they required but did not receive. They were asked to elaborate and explain what effect the assistance, or lack thereof, had on their well-being.

family adaptation, that is, a new level of balance, harmony, coherence, and a satisfactory level of functioning (McCubbin & McCubbin, 1991). Thus, those families who show greater evidence of coping behaviours should experience less stress and less mood disturbance. The biographical questionnaire attempted to test this assertion by evaluating the association between coping behaviours and stress experienced by the caregiver. Coping mechanisms are important in Lezak's (1986) model since she links them to stages of recovery in the head-injured patient. The section of the questionnaire concerning potential coping behaviours were constructed by adopting questions from Kosculick's (1994) Frequency of Family Coping Behaviours (FCB) rating form and from the Family Adaptability and Cohesion Evaluation Scales (FACES-III; Olsen, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1985) with its theoretical base, the Circumplex Model of family and marital systems (Olsen, Russell, & Sprenkle, 1983). Both of these questionnaires utilise the frequency of use of behaviours as a measure of family coping, although this may not be accurate (Kosculick, 1994). In the present study, participants were asked whether or not the behaviour was present, rather than assessing the frequency of it.

Three central dimensions of family behaviour emerge from a conceptual clustering of over 50 concepts developed to describe marital and family dynamics, namely family cohesion, adaptability, and communication (Olsen, 1988). Family cohesion is defined as the emotional bonding that family members have toward one another, while family adaptability is concerned with the extent to which the family system is flexible and able to change. Communication facilitates movement on the other two dimensions. The biographical questionnaire included questions regarding these dimensions. Family cohesion was assessed by inquiring about (a) the supportiveness within the family in terms of helping the caregiver care for the patient, and (b) the feelings of emotional closeness, before and after the injury, so it could then be assessed if the head injury had impacted on feelings of closeness. Also, asking about pre-injury functioning is important since families that were dysfunctional prior to injury may be at greater risk for post injury problems than previously well-adjusted families (Kreutzer et al., 1990b). Adaptability was assessed by examining whether rules and ways of handling tasks changed in the family. The caregiver was also asked if it was possible to express feelings

4.2.4. BIOGRAPHICAL QUESTIONNAIRE

In the research on head injury and the family, many researchers have developed their own checklists or structured interviews to deal with specific problems associated with their particular area or population of interest (Brooks, 1991). As a result, there were no checklists or questionnaires available which were relevant to the present research question, particularly since so little work has been done to empirically test developmental stage models. Thus, the researcher had to construct her own questionnaire after a review of the appropriate literature. This procedure does, however, result in all the common psychometric problems of reliability, validity, and generalisability. Thus, the questionnaire was used in conjunction with other well-used measures, rather than in isolation.

The questionnaire was comprised of both closed and open-ended questions. Open-ended questions allowed the researcher to explore the caregiver's experiences, perceptions, and level of adaptation in some depth. Caregivers were encouraged to elaborate on issues in their own way to allow the researcher to obtain a greater understanding of the nature of the stresses endured which may not have been fully assessed through the use of specific questionnaires.

In addition to ascertaining basic demographic information about the patient and his/her family, the questionnaire asked for information concerning sources and level of stress. A family that is already under stress from other reasons may be more at risk for difficulties. Also, since family reactions to head injury evolve and are resolved over a long-term period, families seldom deal with the head injury in isolation (Kosenilek et al., 1993). Caregivers were also asked if the patient's relationship with her/his parents, siblings, extended families, and friends had improved, not changed, or worsened since the injury (Brown & Nell, 1992).

Given the focus in the literature on the need to identify how the family system copes with a member's head injury, some attempt was made to uncover the dimensions which may underlie such coping. It has been argued that family coping facilitates positive

1985). Considering that this instrument measures transient emotional states, test-retest reliabilities should not be extremely high (Jacobs & Ilaze, 1993).

The original POMS consisted of 65 items and it was argued that its length may limit its use with physically ill or otherwise impaired individuals or prevent its inclusion in multi-instrument assessment protocols (Curran et al., 1995). The first point regarding the original scale's length was not a consideration in the present study since the POMS was completed by unimpaired caregivers, however, a shortened version, which can be administered in approximately half the time as the original scale, was preferred, particularly when one considers the length of the KAS-R. Shacham (1982) found that the correlation for both Total Mood Disturbance and subscale scores between the original and the shortened scales was very high (all above $r = 0.95$). Each of the six scales was reduced by two to seven items without losing internal consistency, and for some scales like Confusion and Tension the internal consistency was improved.

Given the limited sample on which the POMS-SF was developed (83 cancer patients), Curran et al. (1995) assessed its psychometric properties using 609 respondents representing five different clinical samples and one sample of healthy adults. For all samples, internal consistency estimates for the POMS-SF subscales were very comparable, and in some cases (i.e., Tension and Confusion), were actually superior to that of their counterparts in the original POMS. Furthermore, like Shacham's (1983) own findings, correlations between Total Mood Disturbance and subscale scores on the POMS-SF and those from the original POMS all exceeded .95. It was concluded that the short version is an excellent alternative for the original scales when a brief measure of psychological distress is desired. Although the lack of normative data with the original scales is a drawback with the POMS-SF, the POMS-SF is suitable if the primary research question involves the identification of variables associated with variance in POMS-SF scores (Curran et al., 1995). The POMS-SF can therefore be considered an appropriate measure for the present study, since an attempt is made to identify which patient or family variables are associated with caregiver distress, as measured by POMS-SF.

In the present study, data were analysed for differences between patients' and caregivers' perceptions. For each caregiver-patient pair, the difference between the two reports for each item was calculated. Extreme discrepancies between these reports indicated that for any single item, the caregiver's response was at the opposite end of the continuum to that of the patient. In other words, there was a difference of 5 points between the 2 reports. Severe discrepancies indicated that for any single item, the responses of the caregiver differed to that of the patient by 4 points; moderate discrepancies differed by 3 points, mild discrepancies by 2 points, and very mild by only 1 point.

4.2.3. PROFILE OF MOOD STATES (POMS)

The Profile of Mood States - short form, (POMS-SF; Shacham, 1982) was administered to the primary caregiver to assess the degree of stress experienced. This scale is a list of 37 adjectives on which the subject is requested to describe his or her feelings over the past week including the day of the test, on a 5-point Likert scale format, ranging from '0-not at all' to '4-extremely'. A total score for each caregiver was obtained by summing the responses for each item. Total scores range from 0 to 185, and the lower the score, the less the mood disturbance. These scores were used to correlate the caregivers' mood disturbances with the other measures.

The POMS-SF was chosen since it assesses those mood states which Lezak (1986) describes in her conceptualisation of the stages through which families go following brain injury. It was thus possible to ascertain whether those reactions specified by Lezak are actually found in the present sample.

The original POMS is one of the most widely used self-report instruments for the measurement of psychological distress in a variety of clinical and non-clinical populations (Curran et al., 1995; Jacobs & Boze, 1993). It possesses adequate psychometric properties with internal consistencies (Cronbach alpha coefficients) in the range of .84 to .95, satisfactory validity and reliability (Lezak, 1995), and test-retest reliabilities for non-clinical samples have been reported in the range of .65 to .74 (Boyle,

KAS-R4 and KAS-R5 both involve the same list of 22 free-time activities. These include hobbies, social and community activities, and self-improvement activities. For KAS-R4, items are rated by the relative on a 3-point scale indicating whether the patient has been involved in an activity '1-frequently', '2-sometimes', or '3-practically never'. The total score consists of the sum of ratings of individual items. In KAS-R5, the relative indicates whether he/she is satisfied with what the patient does, would like to see him/her do more, or would like to see him/her do less of a given activity. A 2-point scale is used, with the latter two categories scored as 'dissatisfaction', and the first category scored as 'satisfaction'. The sum of ratings for the individual items constitute the total score.

The present study was concerned with the amount of change perceived in the patient and the effect this has on the primary caregiver. It was considered inappropriate to use the item clusters and factors from R1 in this analysis, particularly with the more qualitative approach applied to the small sample size. The difference between the 'before' and 'after' ratings was viewed as more relevant than separate total scores for each section. For each subject, the extent of change on each item (regardless of the direction) was obtained by calculating the difference between the 'before' and 'after' ratings. These were summed to provide the total extent of change on each section.

4.2.2. BIPOLAR PERSONALITY ADJECTIVE SCALE (BPAS)

The 28-item Bipolar Personality Adjective Scale (Jansen, 1988) was used to obtain information on psychological outcome where patients report their self-perceptions and caregivers report their perceptions of the patient. The list of 28 bipolar items was constructed by selecting adjectives from the relevant literature concerning changes in character after TBI (Jansen, 1983). Each item is measured on a 1 to 6 scale, with higher scores indicate greater personality difficulties. Total scores range from 28 and 168 and are calculated by summing the scores for each item. Factor analysis has shown that all items on the Bipolar Personality Adjective Scale when rated by both subject and caregiver loaded on a single factor related to recovery after TBI (Brown & Nell, 1992).

been used in studies describing emotional distress, social adjustment, and general quality of life following head injury (McSweeny, 1990). Lezak (1995) asserts that the issues included in this scale have particular relevance for head trauma victims living with their families or in non-institutionalized settings.

The KAS-R consists of five major subscales, each designed to assess a different aspect of the relative's perception of the patient quality of life. In this study, Wade's (1992) approach was used which asks the relative to mark each item with a circle (O) on the line which best describes the injured person as s/he is *now*, as well as with a cross (X) on the line which best describes the injured person as s/he was *before* the injury. This method is essential to assess *change* in the patient since the injury.

The first section (KAS-R1), which has received the most attention in the assessment of neurobehavioural functioning, contains 127 items which depict numerous psychological, emotional, and behavioural characteristics, for rating on a scale ranging from '1-almost never' to '4-almost always'. Three major factors with 12 factors scales have been drawn from KAS-R1 (Katz & Lyerly, 1963), which can provide discriminating information about head-injured patients although not always on the same factor scales or to the same degree (Lezak, 1995).

The second section (KAS-R2) consists of a list of 16 activities to describe the patient's level of performance in socially-expected behaviours. These include family and social responsibilities, social activities, self-care, home adjustment, and community activities (Katz & Lyerly, 1963). Relatives must rate items on a 3-point scale: '1-is not doing', '2-is doing some', and '3-is doing regularly'. Items are then summed for a total score. An identical list is given for KAS-R3, but in this case the relative is asked to indicate whether, for a given activity, he/she expected the patient to be doing this within a reasonable time following discharge from the hospital. As with KAS-R2, items are rated on a 3-point scale and summed for a total score. The item scale format is '1-did not expect him/her to be doing, '2-expected him/her to be doing some', and '3-expected him/her to be doing regularly'.

catered for the physically disabled or mentally retarded patient, such places for head-injured individuals were severely lacking. Subjects were ultimately obtained from 5 institutions, namely: the Barney Hurwitz Rehabilitation Centre, the University of Pretoria, Milpark Hospital, Access College, and a medico-legal practice. Records were obtained from the institutions and appropriate subjects were telephoned, given a brief overview of the study, and requested to participate. This approach was largely problematic, however, especially due to the long period of time since injury. Many individuals had moved or their telephone numbers had changed, thereby preventing contact with probable subjects. Furthermore, 3 caregivers reported that the patient did not want to be reminded of the injury and thus refused to participate; and another family member reported that the head-injured individual had committed suicide 3 months previously. As a result of all these factors, the sample size was significantly limited. Only eight primary caregivers were involved, 6 (75%) of which were mothers and 2 (25%) were fathers.

4.2 INSTRUMENTS (SEE APPENDIX A)

4.2.1. KATZ ADJUSTMENT SCALE - RELATIVES' FORM (KAS-R)

Neurobehavioural adaptation following head injury has a significant effect on outcome. Goran and Fabiano (1993) assert that although there have been considerable innovations in terms of instrumentation to delineate neuropsychological changes following TBI, there has been little agreement on an instrument to measure psychosocial or behavioural changes. Such changes in the patient have relevance for rehabilitation and therefore need to be objectively assessed. A number of researchers (see Goran & Fabiano, 1993) have reported that the KAS has some utility in the assessment of neurobehavioural functioning following TBI. In the present study, the primary caregiver was required to complete the Katz Adjustment Scale - Relatives' Form (KAS-R; Katz & Lyerly, 1963), which was designed to assess the personal, interpersonal and social adjustment of psychiatric patients as perceived by others. The questionable objectivity of using a close relative as an informant led to the development of items concerning specific behaviours rather than putting the relative in the position of judging the patient. The KAS-R has

CHAPTER FOUR - METHODOLOGY

4.1. SAMPLE

The population of interest in this study was families with a member with a severe closed head injury, leading to a post-traumatic amnesia (PTA) of more than 2 weeks and/or a Glasgow Coma Score of eight or less with a coma duration of more than 6 hours.

The original intention of this study was to examine the effects of head injury which occurred in adolescence (13-19 years). However, due to the extreme difficulties of obtaining such subjects, this age group had to be extended. As a result, age at injury in the sample obtained ranged from 16 years, 11 months to 21 years, 6 months. This slightly older age group is unlikely to alter the theoretical underpinnings of the study regarding the effects that adolescent head injury has on parents. The family is still likely to have the same expectations for their 21 year old child as their adolescent child in terms of independence and a successful adult status.

The sampling procedure required that the family member who was the primary caregiver of the person with the head injury complete study materials, that the families were English-speaking or had a sufficiently good command of the English language to fully comprehend the various questionnaires, and that the head-injured person was between 1 and 5 years post injury.

The sample was drawn from both private and government institutions in the Johannesburg and Pretoria area. Permission was obtained from the relevant authorities. Although the study had aimed to assess individuals of all race groups, all families were White, except for 1 Coloured family. Out of approximately 50 individuals or institutions that were initially approached, only a very small number were able to provide assistance for the present study. This was due primarily to the strict selection criteria applied in the study. Furthermore, while there appeared to be a number of institutions which

greater mood disturbance in the caregiver;

- whether greater personality disturbances, as perceived by the caregiver, would result in higher levels of stress experienced by the caregiver, and;

- whether there would be a significant difference between the reports of the patients and those of their caregivers regarding the patient's personality characteristics; and if so, would this be associated with greater mood disturbance in the caregiver.

B) IS LEZAK'S (1986) DEVELOPMENTAL STAGE MODEL APPLICABLE TO A SOUTH AFRICAN POPULATION AND, WHAT OTHER FACTORS ARE LIKELY TO HAVE AN IMPACT?

In particular, the researcher wanted to explore:

- if families' responses to a member's head injury are aptly characterised by a developmental stage structure, both in terms of the distinct sets of cognitive, behavioural, and emotional reactions, as well as the adaptation patterns that occur at distinct time intervals (Rape et al., 1992);

- what effect coping behaviours and sources of stress had on the caregiver's functioning, and;

- what assistance is available in South Africa for families of head-injured individuals. The nature of any such support and its impact on the functioning of the family was examined.

CHAPTER THREE - AIMS

This study aimed to assess caregivers' experiences of severe head injury in the patient 1-5 years post injury and to contribute to a greater understanding of the nature of a caregiver's distress in a South African population. The intent was to explore the presence of difficulties and disabilities in an adolescent or young adult with brain damage and to record the effects of these on the primary caregiver. It was hypothesised that parents of patients in this age group would have particular concerns related to the stage of development of their child (as discussed in Section 2.2.5. above). The primary aim of the study was to examine the caregiver's level of adaptation to a family member's head injury, and to discuss this in terms of Lezak's (1986) developmental stage model. Due to the significant relationship between changes in the patient and family levels of adjustment, it was first necessary to examine the various changes which occurred in the patient and the impact of these on the primary caregiver.

Thus, the study was designed to answer the following questions:

A) WHAT BEHAVIOUR CHANGES AND PERSONALITY DISTURBANCES ARE FOUND IN ADOLESCENTS OR YOUNG ADULTS WITH SEVERE HEAD INJURY AND WHAT ARE THEIR EFFECTS ON THE PRIMARY CAREGIVER?

In particular, the researcher wanted to assess:

- whether a greater change (regardless of direction) in the patient's personal, interpersonal, and social adjustment since the injury would be associated with

Silver, 1989). The present study attempted to explore possible correlations of long-term caregiver distress.

According to Lezak's framework, a family 1 year or more post injury could be negotiating any one of the latter four stages. What these stages have in common is the reduction in the family's optimism for the patient's total recovery. Although a few of the hypothesised stages have received some empirical support (i.e, denial, gradual acknowledgement of permanent deficits), Rape et al. (1992) have argued that most of the stages lack empirical support and appear to be based primarily on clinical lore. These researchers believe that studies need to evaluate the extent to which the adaptation patterns of family members support predictions derived from developmental stage models such as Lezak's. My study attempted to assess whether these stages can be usefully applied to a South African population.

5.3 RESULTS OF BIPOLAR PERSONALITY ADJECTIVE SCALE(BPAS)

The difference between parents and patients reports on the BPAS was only obtained in 5 cases. Despite this very small number, it was felt that comparisons between the parents' and patients' results in these 5 pairs were still important given the possibility that large discrepancies between these two sets of reports may be linked to great distress, and less positive adjustment, in the caregiver.

The literature suggests that, particularly with severe injuries, patients are unlikely to be aware of their deficits. Indeed, in the present sample one caregiver commented that although the patient was aware of memory and tactual/motor problems, and slowed speech and reading; there was a lack of acknowledgement of personality changes, which were clearly visible to others. Extreme discrepancies between patient and caregiver reports were uncommon, very mild differences were more likely. Only one caregiver-patient pair exhibited extreme discrepancies; these were for Remember remote events-Forgets remote events, Likes company-Dislikes company, and Cautious-Impulsive, compared to 4 reports (80%) of very mild differences in Concentrates well-Easily distractible. The means for each item for the caregivers and the patients, and the differences between them, are provided in Table 8 overleaf.

5.2.2. KAS-R AND ITS RELATIONSHIP WITH TIME SINCE INJURY

Due to the importance of changes over time in terms of Lezak's (1986) model, the degree of association between time since injury and scores on each of the KAS-R subscales was calculated using Spearman's rank-order correlation. Time since injury and scores for subjects on all KAS-R subscales were reduced to ranks (each variable ranked separately). The association between these ranks was examined in turn by computing the difference (d) between the ranks for each subject and then squaring each of these differences. The sum of the squared differences in ranks and the number of paired observations (N) were then entered into a simplification of the formula for the Pearson product-moment correlation as applied to ranked data (McCall, 1990). Total scores on each section of the KAS-R and their correlation with time since injury are given below in Table 7.

TABLE 7: SPEARMAN'S RANK-ORDER CORRELATION BETWEEN TOTAL SUBSCALE SCORES FOR THE KATZ ADJUSTMENT SCALE & TIME SINCE INJURY

KAS-R SUBSCALES	TIME SINCE INJURY (MONTHS)								r_s
	15	20	22	25	30	38	42	54	
KAS-R1: Patient symptoms & social behaviour	163	86	126	79	150	37	106	130	-0.1
KAS-R2: Level of socially-expected behaviours	10	20	17	5	18	0	2	4	-0.67
KAS-R3: Expectations for socially-expected behaviours	18	36	19	9	20	0	12	20	-0.08
KAS-R4: Level of free-time activities	3	25	3	0	10	2	1	15	-0.17
KAS-R5: Dissatisfaction with free-time activities	11	20	12	5	14	0	7	8	-0.5

These results indicate that although there was a tendency for change in the patients' behaviour to decrease with time, this did not reach statistical significance.

the patient's ability to entertain friends at home: 62.5% of parents did not expect their child to do this after the injury. Fifty percent of patients were not doing so since their accident.

By calculating, the discrepancy between the expectations (R3) and activities (R2) scores, the level of parents' satisfaction with performance could be ascertained. This was done for both pre- and post injury reports, which were then compared to provide an index of the change in the level of this dissatisfaction. For KAS-R8, change in the level of dissatisfaction with free-time activities since the injury was assessed directly. Behaviours most likely to be linked with dissatisfaction in the relative since the injury are shown in Table 6 below.

TABLE 6: SOCIAL & LEISURE ACTIVITIES MOST LIKELY TO RESULT IN DISSATISFACTION IN THE CAREGIVER

MEASURE	ITEM	% OF CAREGIVERS EXPRESSING DISSATISFACTION
KAS-R3 - KAS-R2	2.Visits for his friends	62.5
	15.Works	62.5
KAS-R8	3.Works on some hobby	87.5
	14.Visits friends	87.5
	10.Entertain friends	62.5

There is a great deal of overlap between this table and Table 5. When one considers these tables together, although there were a number of activities in which great changes were observed following the injury, not all of these result in significant dissatisfaction in the parent. As can be seen in the table, the main source of dissatisfaction for parents is the patients' relationships with their friends. These results are understandable in terms of the patients' age or stage of development, when strong peer relationships are prominent. This also applies to working on a hobby or going to work.

Severe change indicates that the patient is not doing an activity which s/he was performing before the injury. Moderate change implies that, for any particular activity, patients are only sometimes engaging in it at present, whereas previously it was exhibited frequently. Of these behaviours in Table 8, item 9 and item 2 of KAS-R2 were the most recurrent severe changes. The former was also the most frequently reported moderate change, together with 'Remembers to do important things on time', both of which were reported by 50% of the caregivers. For KAS-R4, 'Work on some hobby' and 'Go to school' fell in to the category of the most frequently reported severe changes, with 50% of relatives reporting a decrease in these behaviours since the injury. 'Write letters' was the most common moderate change, reported by 62% of the parents.

In all of the above cases, patients performed the socially-expected and free-time activities less frequently than before the injury. This is true for all items of KAS-R2 and KAS-R4, including those not represented in Table 8, except for a few interesting cases. Four instances of increases in the frequency with which the patients attended church or assisted with community work was evident, one of which was a substantial change. There was also one report of a slight increase of work in and around the house, of work in the garden or yard, and of playing cards or other table games. These increases are probably indicative of the great amount of time spent at home. The focus on difficulties in relationships with friends is noteworthy, and it links back to the high reports of loneliness in KAS-R1. Similarly, the lack of involvement shown by the patients in Table 8 links back to the lack of interest in things reported in KAS-R1.

KAS-3 measures the level of expectations for performance of social activities. Subjects were asked to record their expectations of their child for both before and after the injury. For many parents, their expectations regarding their child's ability to function changed in a number of areas following the head injury. In all cases of the present study, any change in expectations indicated that parents expected less of their injured children following the head injury. In some cases, the patient was performing certain activities that the caregiver had not expected were possible. The most frequently reported change in expectations concerned

The high reports of childish and less responsible behaviour is in keeping with the literature. Such behaviour usually makes interpersonal relationships very difficult, as suggested by the large proportion of patients who felt lonely. In terms of the extent of the change, the most frequently observed severe change (reported by 50% of caregivers) was 'Feels lonely'; the most frequent moderate changes (reported by 50%) were 'Has trouble sleeping','Gets very sad, blue', 'Shows her/his feelings' and 'Shows good judgement'; and the mild change most often reported (by 62.5%) was 'Acts helpless'. Patients were less likely to show good judgement and more likely to exhibit the other behaviours.

KAS-R2 and KAS-R4 measure the level of performance of socially expected activities and the level of free-time activities, respectively. The most frequently observed changes in patients measures are presented in Table 5 below.

TABLE 5: MOST FREQUENTLY REPORTED CHANGES IN PATIENTS' SOCIAL & FREE-TIME ACTIVITIES

	ITEM	SEVERE CHANGE	MODERATE CHANGE
		NO. OF CAREGIVERS REPORTING	
KAS-R2	9.Goes to parties & other social activities	3(37.5%)	4(50%)
	1.Helps with household chores	2(25%)	3(37.5%)
	2.Visits her/his friends	3(37.5%)	2(25%)
	7.Remembers to do important things on time	1(12.5%)	4(50%)
KAS-R4	3.Work on some hobby	4(50%)	2(25%)
	6.Write letters	0(0%)	5(62.5%)
	7.Go to the movies	2(25%)	3(37.5%)
	12.Bowl or other sports	3(37.5%)	3(37.5%)
	15.Visits friends	2(25%)	4(50%)
	16.Entertain friends	3(37.5%)	4(50%)
	18.Read	1(12.5%)	4(50%)
	22.Go to school	4(50%)	0(0%)

decrease was shown in each of the following: loneliness, feelings being easily hurt, sadness, talking too much, and complaints of physical ailments. Two parents reported that slightly less anger was evident in their children. The only large unexpected change was a marked decrease in the amount of attention necessary for one patient since the injury.

TABLE 4: MOST FREQUENTLY REPORTED CHANGES IN PATIENTS' SYMPTOMS & BEHAVIOUR

ITEM	SEVERE CHANGE	MODERATE CHANGE	MILD CHANGE
	NO. OF CAREGIVERS REPORTING		
1. Has trouble sleeping	0(0%)	4(50%)	0(0%)
4. Feels lonely	4(50%)	3(37.5%)	1(12.5%)
17. Needs to do things slowly to do them right	3(37.5%)	2(25%)	3(37.5%)
3. Acts as if s/he has no interest in things	1(12.5%)	1(12.5%)	4(50%)
8. Just sits	2(25%)	1(%)	4(50%)
11. Feelings get hurt easily	3(37.5%)	2(25%)	2(25%)
15. Gets very sad, blue	1(12.5%)	4(50%)	4(50%)
28. Gets angry & breaks things	1(12.5%)	2(25%)	4(50%)
34. Gets very excited for no reason	1(12.5%)	3(37.5%)	3(37.5%)
38. Shows his/her feelings	0(0%)	4(50%)	2(25%)
41. Complains of headaches, stomach trouble & other physical ailments	1(12.5%)	1(12.5%)	4(50%)
63. Is responsible	2(25%)	3(37.5%)	3(37.5%)
66. Shows good judgement	1(12.5%)	4(%)	2(25%)
72. Needs a lot of attention	1(12.5%)	2(25%)	1(12.5%)
73. Behaviour is childish	2(25%)	3(37.5%)	2(25%)
74. Acts helpless	0(0%)	0(0%)	5(62.5%)
91. Acts as if s/he can't get certain things out of her his mind	2(25%)	1(12.5%)	4(50%)
106. Talks too much	2(25%)	1(12.5%)	4(50%)
131. Talks about big plans s/he has for the future	0(0%)	3(37.5%)	4(50%)

TABLE 3: BIOGRAPHICAL INFORMATION ABOUT THE CAREGIVER

SUBJECT NO.	HOME LANGUAGE	AGE RANGE	RELATIONSHIP TO PATIENT	HIGHEST EDUCATION	WORKING BEFORE	WORKING AFTER
1	English	31-40	Mother	Matric	Yes	Yes
2	Afrikaans	41-50	Mother	Matric	Yes	Yes
3	Afrikaans	41-50	Mother	Matric	Yes	No
4	Afrikaans	31-40	Mother	Some College	Yes	Yes
5	English	41-50	Mother	Std 8	Yes	No
6	English	41-50	Father	Some University	Yes	Yes
7	English	41-50	Mother	Matric	Yes	No
8	Afrikaans	51-60	Father	University graduate	Yes	Yes

5.2 RESULTS OF THE KATZ ADJUSTMENT SCALE

5.2.1. CHARACTER AND FREQUENCY OF CHANGES

One of the aims of this study was to assess what changes were most frequently observed in patients with severe brain damage 1-5 years post injury. This was appraised by KAS-R1, KAS-R2, and KAS-R4, which asked for caregiver responses about the patient's symptoms and social behaviour both before and after the head injury.

For KAS-R1, the most frequently reported changes in patients' behaviours since the injury, are recorded in Table 4 overleaf. If there was a substantial difference in the frequency with which a behaviour was performed post injury, as compared to pre-injury (e.g., if the patient never engages in an activity that s/he had previously almost always performed), these responses were classified as severe changes. If there was a slight difference, responses were recorded as mild changes; with moderate changes falling between these two.

In most cases, the changes occurred in the expected direction, that is, there was an increase in the frequency of negative behaviours and a decrease in positive behaviours. However, for some patients this did not apply and changes can be viewed as improvements. A mild increase in the level of responsibility was shown by one patient, while one report of a mild

TABLE 2: BIOGRAPHICAL INFORMATION ABOUT THE PATIENTS

SUBJECT No.	AGE AT INJURY	TIME SINCE INJURY (MONTHS)	COMA LENGTH (DAYS)	SEX	EDUCATION BEFORE	EDUCATION AFTER	WORK BEFORE	WORK AFTER
1	19.16	19	14	M	Matric	Matric	Part time	None
2	20.5	20	210	M	Some university	Some university	Part time	None
3	21.9	32	30	M	Some college	Some college	Part time	None
4	19.08	25	8	M	College graduate	College graduate	Full time	Full time
5	20. 08	30	32	M	Matric	Matric	Full time	None
6	16.0	38	28	M	Std 9	Matric	None	None
7	20.33	42	30	F	Some university	University graduate	Part time	None
8	20.5	84	21	M	Some university	University graduate	Part time	None

As is typical of the head-injured population, sex ratios were skewed (Kreutzer et al., 1994a). With a single exception, all patients were male (87.5%). Three patients (37.5%) had returned to their studies since the injury, but only one individual (12.5%) had returned to any form of work. Understandably, it is the 3 patients with the longest time since injury that returned to their studies suggesting that it may only be possible to do so 3 or more years post injury.

5.1.2. BIOGRAPHICAL INFORMATION ABOUT THE CAREGIVERS

Similar to other head injury family studies, the primary caregivers were predominantly mothers (75%). Most of the sample fell into the age range of 41-50 years (62.5%), with 2 mothers in the 31-40 age range (25%), and one father in the 51-60 age range (12.5%). There were equal numbers of English- and Afrikaans-speaking participants. In terms of the caregivers' education levels, one parent had reached the level of standard 8 (12.5%), 4 had matriculated (50%), 2 had some university/college education (25%), and only 1 was a university graduate (12.5%). All parents had been working before their child's injury, but not all were currently working. Three mothers (37%) had given up their jobs to care for the injured family member which seemed undetermined by time since injury.

CHAPTER FIVE - RESULTS

5.1 BIOGRAPHICAL INFORMATION

Information was obtained for 8 primary caregivers and their head-injured children. This is provided in Table 2 and Table 3. Given the importance of time since injury in the present study, subjects are numbered according to time since injury, that is, Subject 1 is the patient who was injured most recently and Subject 8 has the longest time since injury. This allows for a clearer picture of the course of difficulties and recovery over time.

5.1.1. BIOGRAPHICAL INFORMATION ABOUT THE PATIENTS

All head injuries in the sample were due to motor vehicle accidents. The patients' age at injury ranged from 16 years and 11 months to 21 years and 6 months, mean 19.75 (*SD* = 1.39). Time since injury ranged from 15 to 84 months, mean 30.75 (*SD* = 13.06). All patients in the study were very severely injured. In terms of severity measures, only coma duration could be obtained for all subjects. Complete hospital records were unavailable in most cases and caregivers were generally uninformed about GCS scores or PTA. Consequently, the researcher had to rely predominantly on caregivers' reports of length of coma, which were often sketchy. Coma duration was defined as the time between injury and the resumption of consciousness, and ranged from 8 days to 215 days, mean 49.13 (*SD* = 68.06). The large range is due to one patient who was in a coma for 210 days. Without this individual, the coma length of the sample ranges from 8 days to 35 days, mean 25.43 (*SD* = 11.82).

measurements are not made with interval or ratio scales. Cooper and Emory (1995) point out that as a special form of Pearson's product-moment correlation, this procedure's strengths outweigh its weaknesses. It is unaffected both by transformations in the data with logs or squaring and by extreme scores since the largest number in the distribution is equal to the sample size. It is however, sensitive to tied ranks, with too many ties distorting the coefficient's size. Fortunately, this is not a frequent occurrence.

The responses in the biographical questionnaire were analysed qualitatively. Descriptive statistics using percentages and proportions were employed for the closed-ended questions as it was not be possible to calculate means and standard deviations, etc. Common themes were extracted from the open-ended questions. Thus, two inter linked areas of data were obtained. In this way, data from the closed-ended questions could be elaborated on with information from the open-ended questions.

4.4. ANALYSIS

Due to the small sample size, the information obtained was of a qualitative nature. Scores on each of the questionnaires were calculated. Descriptive statistics using percentages were employed to assess frequencies of various patient behaviours (on the KAS-R), personality characteristics (on the BPAS) and caregiver reactions (on the POMS).

For the Bipolar Personality Adjective Scale, the mean score for each item was calculated separately for relatives and for patients. The most frequently observed personality characteristics to be found in a head-injured sample of adolescents or young adults, according to both the caregiver and the patient, could thus be assessed. The differences between these two means revealed which items show the largest differences between parent and patient reports. Test totals were compared using Wilcoxon's matched-pairs test. This test is the distribution-free analogue of the *t* - test for related samples (Howell, 1989), it has excellent efficiency and can actually be more powerful than the *t* test in cases where the latter is not particularly appropriate. Because of the matched-pairs nature of the data, the small sample size, and the uncertainty regarding the shape of populations distributions, this test was particularly appropriate for this analysis (O.P. Hall & Adelman, 1990).

Those emotions from the POMS which are important in explaining Lezak's developmental stage model were selected and graphed across subjects. This made it possible to witness the course of these emotions over time in the present sample and to compare this sequence to that proposed by Lezak (1986).

Spearman's rank-order correlation was used to assess the degree of association between all the measures, including each subscale of the KAS-R, and these variables' association with time since injury. This enabled the researcher to assess whether behaviour problems and personality difficulties in the patient are related to caregiver distress, as suggested by the literature, and whether there is a change in these factors over time. Spearman's test procedure correlates ranks between two ordered variables and is appropriate when

4.3. PROCEDURE

The design of this study was ex post facto. Such a design simulates an experiment; the difference being that the subjects have been naturally manipulated prior to the study, on relevant factors, so that they can be examined after the fact.

The researcher met with the primary caregivers. They were given an information sheet which indicated that all the data gathered in the study was for research purposes only and that their confidentiality was ensured. They were then requested to sign a consent form which stated that they were under no obligation to participate and that they could discontinue participation at any time without prejudice towards them.

All questionnaires for the caregiver were completed in the presence of the researcher and were administered in the same order to all participants, that is, the Katz Adjustment Scale - Relatives' Form (KAS-R), Bipolar Personality Adjective Scale (BPAS), the Profile of Mood States (POMS) and then the biographical questionnaire. This latter measure was verbally administered to the primary caregiver. Injury data was obtained from the caregiver as far as possible, or from the institutions' records, if available.

Patients were also asked to fill in the BPAS. However, completed questionnaires could only be obtained from 5 of the 8 injured patients. In four cases, the patient completed the Bipolar Personality Adjective Scale with the researcher present, while one was returned completed at a later date due to the unavailability of the patient at the time of assessment. Of the 3 patients for which questionnaires were unavailable, one individual studied away from home and was thus engaged at the time of testing, another patient resided in a nursing home and was too severely injured to respond to any assessment, and in the final case the caregiver stated that the patient's responses were likely to be extremely unreliable.

5.5.2. FAMILY COPING BEHAVIOURS

According to the literature certain behaviours are considered t assist family coping after severe stress, such as head injury. Aspects of coping assessed in this study included feelings of closeness between family members, participation in family activities, ability to express feelings within the family, flexibility in family rules, and supportiveness among family members as manifested by sharing the role of caring for the patient. Percentages of parents who showed evidence of these activities are recorded in Table 12 and Table 13 below.

TABLE 12: PERCENTAGE OF CAREGIVER EXHIBITING COPING BEHAVIOURS PRE- & POST INJURY

METHODS OF COPING	BEFORE			AFTER		
	PRESENT	TO SOME EXTENT	ABSENT	PRESENT	TO SOME EXTENT	ABSENT
CLOSENESS	100%	0%	0%	87.5%	12.5%	0%
FAMILY ACTIVITIES	62.5%	37.5%	0%	37.5%	50%	12.5%

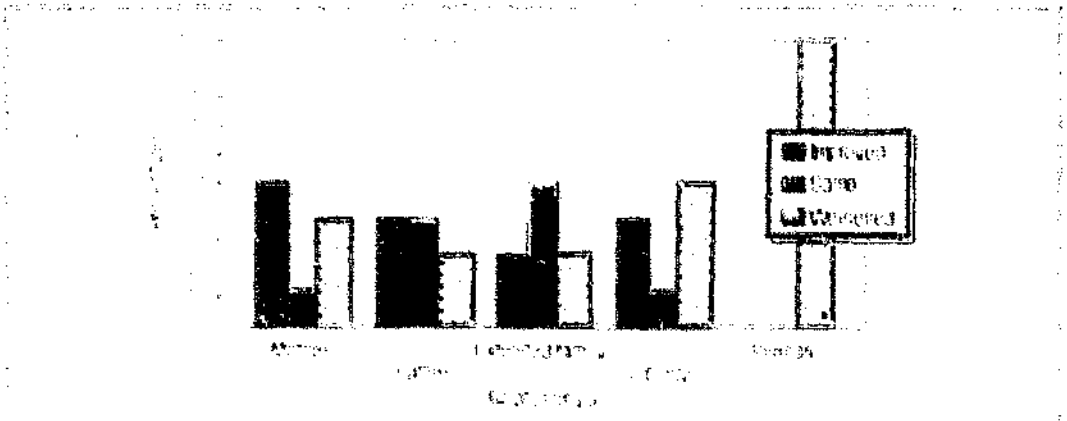
All families were reported to have been close before the injury and in only one case feelings of closeness lessened since the injury. Although feelings of closeness and a wish to be with each other was evident, one parent reported that in practice, closeness among family members was impossible because it was so difficult to relate to the patient. This may explain the reduction in family activities since the injury.

TABLE 13: PERCENTAGE OF CAREGIVER REPORTING COPING BEHAVIOURS

METHODS OF COPING	PRESENT	TO SOME EXTENT	ABSENT
EXPRESSION OF FEELINGS	87.5%	0%	12.5%
RULE FLEXIBILITY	62.5%	12.5%	25%
SUPPORTIVENESS	62.5%	0%	37.5%

Most caregivers (87.5%) felt that they could express their feelings openly in their family. Although one caregiver felt that the expression of anger was not constructive, the ability to

FIGURE 8: CHANGES IN THE PATIENTS' RELATIONSHIPS WITH OTHERS



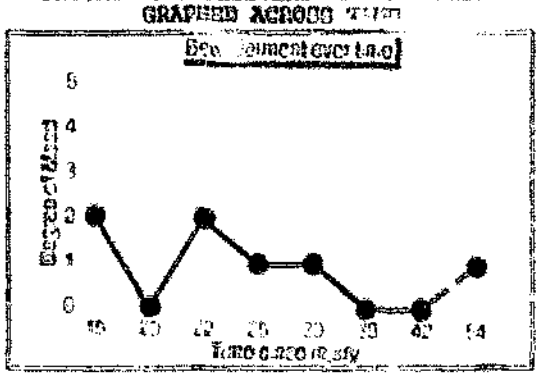
It would seem that sibling relationships do suffer as a result of a head injury in the family. Four parents (50%) reported that the patient's relationship with his/her siblings had worsened since the injury. It was suggested that this may be the case because of the reduction in the patients' tolerance level since the injury. For one patient, it was emphasised that the relationship with siblings had deteriorated substantially. However, in 3 cases (37.5%), there was an improvement in this relationship.

The most significant finding was in terms of the patient's relationship with his/her friends. All patients had lost their friends since the injury. Parents emphasised that this loss of peer relationships was particularly painful, and perhaps the most difficult change, for the patient. Friends were reported to have been very unsympathetic, and had difficulty in dealing with the patient's strange, different, and often inappropriate behaviour. There was a lack of communication between the patient and his/her friends after the injury.

5.4.2.7. Bewilderment Over Time

Families are typically bewildered by the patient's strange behaviour soon after they return from hospital. In Lezak's (1986) framework, this bewilderment is likely to continue until the family reaches a full awareness of the patient's deficits in the fourth stage. According to the graph, stage 4 is likely to begin at approximately 22 months after the injury.

FIGURE 6: CAREGIVERS' BEWILDERMENT GRAPHED ACROSS TIME



5.5 THE RESULTS OF THE BIOGRAPHICAL QUESTIONNAIRE

5.5.1. PATIENTS' RELATIONSHIPS WITH OTHERS

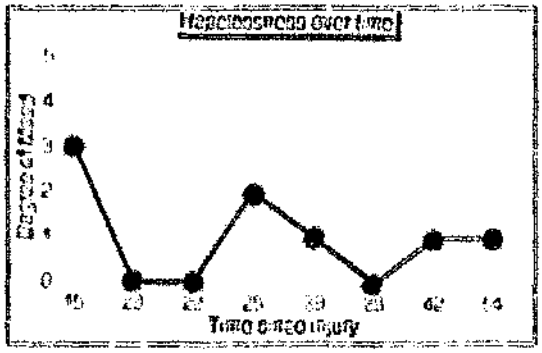
Contrary to much of the literature on family relationships following severe head injury, there was moderate evidence to suggest improvement in a number of areas, as shown in Figure 8 overleaf.

Five caregivers (62.5%) reported that their own relationship with their child had improved since the injury. Four of these parents were mothers and one was a father. These parents commented that they felt closer to their child because they were together more and were generally more forgiving or accepting of the patient and his/her behaviour since the injury. In one case, although the mother reported feeling very close to the patient since the injury, she felt that the relationship was limited due the level of disability in the patient. For 1 mother (12.5%) the relationship with her child had remained the same, and for another mother and one father (25%) the relationship had worsened.

5.4.2.5. Hopelessness Over Time

According to the literature and Lezak's (1986) model, hopes for complete recovery diminish at the end of the first year post injury. The high level of hopelessness recorded on the graph at 15 months is therefore understandable. In Lezaks' stages this sense of hopelessness continues through stage 4 and 5 as all hope for recovery of the patient's premorbid personality is relinquished. In the present sample, however, no evidence of hopelessness was seen between 20 and 22 months, although a moderate to mild degree was present between 22 and 38 months. After 38 months, a sense of hopelessness is present in a mild form.

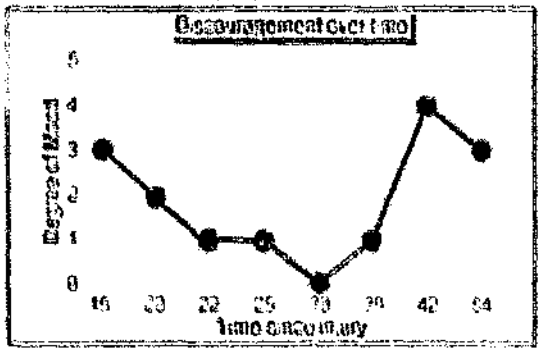
FIGURE 5: CAREGIVERS' HOPELESSNESS GRAPHED ACROSS TIME



5.4.2.6. Discouragement Over Time

According to Lezak (1986), discouragement is common in the last half of the first year post injury as the caregiver fails to improve the worsening situation. It continues into the fourth stage, after which it is no longer present. The graph does show this decrease in discouragement up to 30 months after the injury. Yet, there is a severe increase after this point in time until at 42 months, feelings of discouragement are at their highest. A drop then follows. Lezak's model cannot account for this pattern.

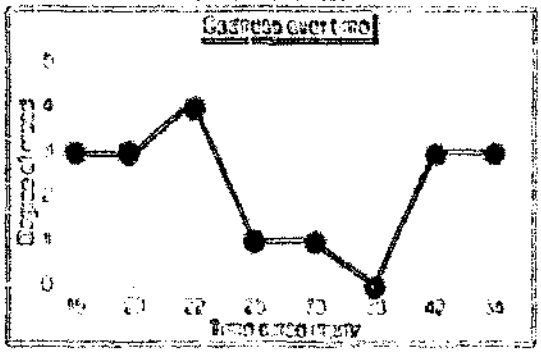
FIGURE 6: CAREGIVERS' DISCOURAGEMENT GRAPHED ACROSS TIME



5.4.2.3. Sadness Over Time

In Lezak's model sadness is present from stage 3 but is likely to be prominent at 15 months in the period of active mourning, and to decrease after this stage. The graph suggests that this period of mourning may be at approximately 22 months followed by the emotional disengagement of the sixth stage. This is possible in Lezak's model. However, once again her model does not explain the findings after 38 months.

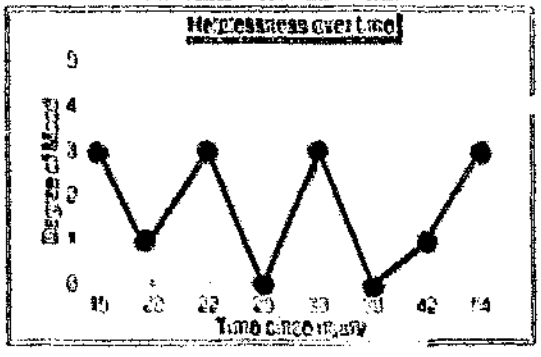
FIGURE 3: CAREGIVERS' SADNESS GRAPHED ACROSS TIME



5.4.2.4. Helplessness Over Time

The large changes seen in the graph may reflect caregiver responses to various improvements and plateaus in the patient's recovery. It does not appear to suggest that a sense of helplessness disappears over time. Lezak (1986) asserts that helplessness is likely to appear in stage 3 when attempts to rehabilitate the patient are frequently unsuccessful. Lez .'s model provides no explanation for the graph.

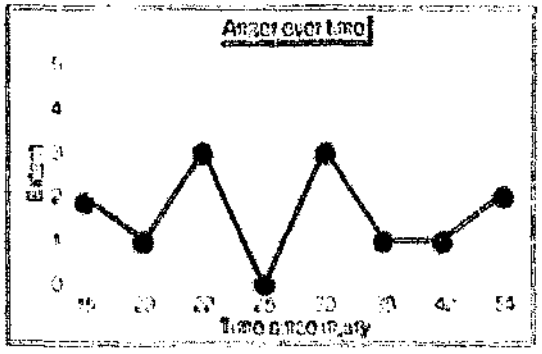
FIGURE 4: CAREGIVERS' HELPLESSNESS GRAPHED ACROSS TIME



5.4.2.1. Anger Over Time

According to Lezak (1986), anger begins in the third stage, continues through the fourth and fifth stage to decrease when the family finally reorganises itself in the sixth stage. The graph suggests rather varying degrees of anger over time which may be related to the emergence of difficult patient behaviours over time. No anger was reported at 25 months which coincides with Lezak's sixth stage. However, following this there is a sharp increase again which cannot be accounted for by Lezak's model.

FIGURE 1: CAREGIVERS' ANGER GRAPHED ACROSS TIME



5.4.2.2. Anxiety Over Time

The change on the graph in levels of anxiety between 15 and 38 months post injury can be explained by Lezak's stages to some extent. According to her model, there may be some uneasiness in the fifth stage (at approximately 15 months) as the caregiver attempts to mourn with the continued frustrating presence of the patient. Following this, mood disturbances on this scale should decrease as the family reorganises itself in the last stage. The changes between 15 and 30 months on the graph could be accounted for if a family struggles initially to reorganise itself. However, the increase in anxiety after 38 months cannot be accounted for by Lezak's model.

FIGURE 2: CAREGIVERS' ANXIETY GRAPHED ACROSS TIME

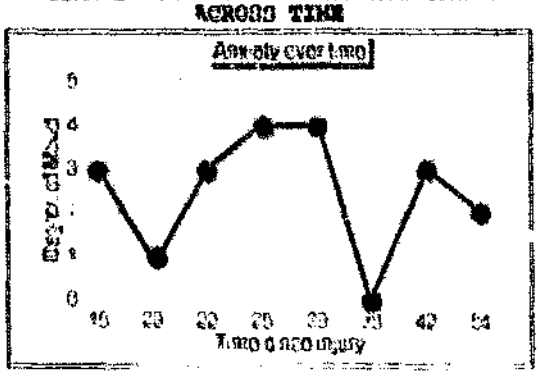


TABLE II: CONTINUED

Factor of Mood	Time since post-natal							
	15	20	22	28	30	38	42	54
Mild	Tense Vigorous Uncertain about things Full of pep Forgetful Active Forgetful	Angry Peeved Annoyed Resentful Mistrustful Anxious Helpless Full of pep Uncertain about things Rushed	Cheerful Tense Vigorous Forgetful Hopeless Bitter Unable to concentrate Fatigued Discouraged Rushed	Forgetful Uncertain about things Vigorous Worn out Full of pep Bewildered Sad Active Discouraged Mistrustful Cheerful	Worn out Forgetful Forgetful Vigorous Exhausted Bitter Resentful Full of pep Bewildered Weary Annoyed Active Hopeless Tense Unable to concentrate Sad Tired	Angry Discouraged	Active Angry On edge Hopeless Resentful Exhausted Helpless	Hopeless Tense Bewildered Uncertain about things

As a group, parents were most likely to report feeling tense, fatigued, exhausted and weary; while they were least likely to report feeling worthless or forgetful. Interestingly, none of these emotions are focussed on by Lezak (1986). Emotions that she does concentrate on were selected from the POMS and graphed so that their presence across time could be visualised and compared to their hypothesised appearance by Lezak. The emotions from the POMS that best coincided with Lezak's model were anger, confusion, discouragement, anxiety, helplessness, bewilderment, sadness, and hopelessness. These are shown in Figures 1-7 overleaf.

5.4.2. CAREGIVERS' MOOD DISTURBANCES OVER TIME

In order assess whether Lezak's (1986) assumptions about the presence and order of particular emotions are correct, caregiver responses on the POMS were placed on a time scale. For each time since injury, all emotions present in that particular caregiver were recorded, according to the degree of the mood experienced. This is shown in Table 11 below.

TABLE 11: CAREGIVERS' EMOTIONS ACROSS TIME

POMS Mood	Time since injury (months)							
	15	20	23	26	30	38	43	54
TENSION	Tense Blue Fatigued		Worn out Unhappy Sad Tense	Restless Anxious Blue Unhappy	Fatigued Uncertain about things Nervous Unsteady Anxious		Discouraged	Worn out Peeved Ready to explode Grouchy Blue Fatigued Annoyed Exhausted Weary
DEPRESSION	Worn out Unhappy Peeved Ready to explode Sad Hopeless Tense Annoyed Exhausted Anxious Helpless Restless Nervous Blue Forlorn Discouraged Resentful Weary Bored	Tense Fatigued Exhausted Worn out Sad Unsteady Ready to explode	Tense Anxious Hopeless Exhausted Resentful Angry Weary Ready to explode Grouchy Confused Peeved Nervous Miserable Blue	Tense Unable to concentrate Fatigued Exhausted Hopeless Tense Confused Weary	Ready to explode Helpless Angry	Tense Fatigued Exhausted Active Energetic Worn out	Sad Grouchy Fatigued Anxious Weary	Tense Unhappy Sad Restless Unable to concentrate Discouraged Resentful Nervous Miserable Bitter Hopeless
VIGOUR/ACTIVITY	Miserable Humiliated Worthless Angry Confused Grouchy Unable to concentrate Unsteady	Unhappy Vigorous Lively Weary Unsteady Active Grouchy Energetic Discouraged Nervous	Humiliated Tense Worthless Uncertain about things Annoyed Energetic Restless Active	Worthless Bored Hopeless Ready to explode	Tense	Vigorous Weary Lively Unsteady	Bitter Forgetful Unsteady Miserable Tense Unhappy Blue Energetic Annoyed Uncertain about things Bored	Angry Unsteady Anxious Furious Forgetful

behaviour (KAS-R), and patient personality characteristics (BPAS). Total scores for these variables are shown below in Table 10. On these scales, high scores indicate greater difficulties. Scores for each variable were ranked separately, and the association between POMS and each of the other measures was examined in turn.

TABLE 10: SPEARMAN'S RANK-ORDER CORRELATION BETWEEN THE PROFILE OF MOOD STATES, KATZ ADJUSTMENT SCALE, BIPOLAR PERSONALITY ADJECTIVE SCALE & TIME SINCE INJURY

OTHER MEASURES	TOTAL SCORES FOR EACH SUBJECT ON THE PROFILE OF MOOD STATES								R_s
	S 1	S 2	S 3	S 4	S 5	S 6	S 7	S 8	
	91	49	84	59	58	28	48	83	
TIME SINCE INJURY	15	20	22	25	30	38	42	54	-0.45[a]
KAS-R1	163	86	126	70	180	27	106	139	0.6[a]
KAS-R2	10	20	17	5	18	0	2	4	0.36[a]
KAS-R3	18	36	19	0	28	0	12	20	0.09[a]
KAS-R4	2	25	3	0	10	2	1	15	0.27[a]
KAS-R5	11	20	12	5	14	0	7	8	0.31[a]
BPAS	129	70	108	89	101	45	88	105	0.95[a]

Note: BPAS = Bipolar Personality Adjective Scale
S = Subject
[a] Non significant
* $p < 0.01$

These results suggest that there is no significant relationship between the total POMS score and time post injury, although there is a tendency for the POMS scores to decrease with time. Furthermore, there is little association between the caregiver's mood disturbance and the patient's symptoms and level of social functioning. The only significant relationship ($p<0.01$) is that between the parents' mood disturbances and the patients' personality characteristics. Greater mood disturbance is strongly associated with more negative personality disturbances. This is in keeping with the literature.

TABLE 9: MAGNITUDE OF DIFFERENCE BETWEEN PATIENT & CAREGIVER REPORTS ON THE BIPOLAR PERSONALITY ADJECTIVE SCALE

PAIR	TOTAL PATIENT SCORES	TOTAL PARENT SCORES	DIFFRENCE	RANK OF DIFFERENCE
1	99	88	11	1
2	98	45	13	2
3	119	89	30	4
4	128	101	27	3
5	83	129	-46	-5
	$T+ = 10$ $T- = -5$	$T = 5$	Non significant	

5.3.2. THE BIPOLAR PERSONALITY ADJECTIVE SCALE AND ITS RELATIONSHIP WITH TIME SINCE INJURY

As with the KAS-R, the association between the BPAS and time since injury was calculated with Spearman's rank-order correlation separately for the parent ($N = 8$) and for the patient ($N = 5$) reports. An r of -0.31 for parent reports and $r = 0.74$ for patient reports indicates that there is no significant relationship between the BPAS and time since injury for either set of responses. It is interesting to note the difference in signs, though. According to the caregivers' reports, it would appear that as time increases after the injury, personality difficulties tend to decrease. The opposite is true for the patients' reports of their own personality difficulties. It may be that the caregivers become more accustomed to the changes in the patient, while patients may become more negative about themselves as little improvement is seen over time.

5.4 RESULTS OF THE PROFILE OF MOOD STATES

5.4.1. POSSIBLE CORRELATES OF THE CAREGIVERS' MOOD DISTURBANCES

Spearman rank-order correlation was used to assess the association between caregivers' mood state, as measured by the POMS, and time since injury, patient adjustment and social

Individual scale items showing the largest differences between parent and patient reports were Talkative-Quiet, Sensitive-Insensitive, Reasonable-Unreasonable, Calm-Excitable. Intelligence was the only item for which there was no difference between the means of the reports. Parents were most likely to report that the patients were easily distracted, reliant on others, changeable, impulsive, liked company, and were talkative. Seventy-five percent of parents reported that patients had severe or moderate difficulties with distractibility and impulsiveness, and 62.5% had severe or moderate difficulties with remembering recent events. Patients were most likely to report that they were easily distracted, changeable, sensitive, and liked company. The mean score for parents' reports was 91.88 (SD = 23.96), and for patients' reports 97.4 (SD = 25.16).

5.3.1. THE DIFFERENCE BETWEEN PATIENT AND CAREGIVER REPORTS

An attempt was made to determine the magnitude of difference between the caregivers' and patients' reports, using the Wilcoxon matched-pairs test (Cooper & Emory, 1995; Howell, 1989). The difference score for each pair of measurements was calculated and ranked without regard to sign. The actual signs of each difference are then assigned to the ranks. Positive and negative ranks were summed separately and the test statistic (T) was taken as the smaller of these value, ignoring the sign. This is shown overleaf(Table 9). There was no significant difference between the patients' and parents' reports regarding the patients' personality characteristics since the head injury.

TABLE 8: COMPARISON OF BIPOLAR PERSONALITY ADJECTIVE SCALE SCORES FOR PATIENTS & CAREGIVERS

ITEM	CAREGIVERS		PATIENTS		
	MEAN	SD	MEAN	SD	DIFFERENCE
Remembers-Forgetsrecent events	3.88	2.03	4.4	1.5	0.53
Remembers-Forgetsremote events	2.88	1.69	3.8	1.72	0.93
Considerate-Inconsiderate	2.5	1.12	2.6	1.85	0.1
Kind-Cruel	1.75	0.83	2.6	1.85	0.85
Happy-Unhappy	3.38	1.8	4.6	1.5	1.23
Reasonable-Unreasonable	3	1.41	4.4	1.85	1.4
Warm-Cold	2.5	1.32	2.4	1.85	-0.1
Rational-Irrational	3.25	1.3	4.2	1.6	0.95
Calm-excitable	3.25	1.85	4.6	1.5	1.35
Likes-DislikesCompany	1.25	0.43	2	2	0.75
Cautious-Impulsive	4.25	1.64	3	2.1	-1.25
Talkative-Quiet	1.63	0.7	3.6	1.74	1.98
Energetic-Lifeless	3.25	1.2	3.2	1.72	-0.05
Generous-Mean	2.75	1.71	3	1.67	0.25
Mature-Childish	4	1	2.8	1.72	-1.2
Charming-Rude	3.13	1.69	2.6	1.85	-0.53
Confident-Hesitant	4.13	1.17	3.2	2.04	-0.93
Enthusiastic-Listless	3.13	0.6	3.2	1.72	0.08
Sensitive-Insensitive	3.5	1.41	2	2	-1.5
Intelligent-Unintelligent	3	1.22	3	1.67	0
Sensible & down to earth-Silly & out of touch	3.38	0.7	3	1.67	-0.38
Clear thinking-Confused thinking	3.5	1.12	4.6	1.2	1.1
Concentrates well-Easily distracted	4.88	1.17	5.4	0.8	53
Relaxed-Tense	4.13	1.62	4.4	1.36	0.28
Creative-Unimaginative	3.38	1.71	2.4	1.02	-0.85
Attentive-Inattentive	3.75	1.09	3.2	1.6	-0.55
Stable-Liable	4.25	1.48	4.8	1.17	0.55
Self-reliant-Reliant on others	4.37	1.43	4.4	1.85	0.03

with their peers expected of this age group.

The finding of patients' lack of involvement in leisure activities is similar to that of Hall et al. (1994) who followed patients for 2 years post injury. Parents in the present study were dissatisfied with the patients' lack of interest in working on a hobby and in going to work. This is understandable in that at this point in their lives young adults are expected to begin their careers and to financially support themselves. The inability to do so adds another role required of the parents - that of providing (perhaps permanent) financial support. The difficulty with this was indicated by the high percentage of caregivers who reported that financial problems were a source of stress. As Jennett and Bond (1975) argue, since many survivors are young, those with severe or moderate damage face many years of handicap and perhaps dependence, and this has important implications.

Peer interaction, working on a hobby, and going to work are all activities expected of adolescents or young adults and the absence of them in the present sample may be particularly dissatisfying for the primary caregivers because this means that they are unlikely to obtain respite from care. As hypothesised by the study, the fact that head injury has thwarted progression into independence, is linked with great dissatisfaction in the caregivers.

The literature suggests that as the severity of the head injury increases, patients are less likely to be aware of their deficits. Due to the severity of the present sample, one would expect that patients would be unaware of their difficulties and thus a large discrepancy between patient and caregiver reports on the BPAS would emerge. However, no significant difference between these reports were found. A similar finding emerged in Brown and Nell's (1992) South African study at 12 months post injury, although at 6 months caregivers rated the patient as more reasonable and less confident than the patients did themselves. The present study also found that caregivers tended to perceive patients as more reasonable than they did themselves, in addition to perceiving them as more calm, more talkative, and less sensitive. Probably due to the inclusion of mild and moderate injuries in their study, the mean scores for each item on the BPAS in Brown

findings are typical of brain-injured samples after head injury, and reflect the emotional change, impaired social perceptiveness, impaired self-control, and increased dependency so frequently reported (Lezak, 1978). The changes in the ability to judge situations and to make appropriate emotional responses would also reflect the underlying neuroanatomical damage to the frontal and temporal regions of the brain. This would help to explain findings in this study, and that by Brooks et al. (1986), of common complaints (in 62.5% of patients) of angry outbursts at 1-5 years post injury. The problems in the initiation, planning, and execution of behaviour which were perceived as a lack of motivation by the parents, can also be accounted for by damage to the frontal regions, through a reduction in autonomous and self-reliant behaviour (Goran & Fabiano, 1993). Furthermore, the problems with anger and sadness reported may be indicative of left hemisphere damage, while the hyperverbosity and tangentiality in some patients may reflect right hemisphere damage.

As a result of these changes in the patient, all patients lost their friends since the injury, as reflected by reports on the biographical questionnaire and it would seem that most patients had not been able to re-establish or develop new friendships since the injury, as reflected by the Katz Adjustment Scale (KAS-R1, KAS-R2, and KAS-R4). Responses on these latter measures showed that visiting and entertaining friends and going to parties and other social activities underwent a marked decrease since the injury, and as a result, all patients were perceived as being lonely.

In essence, what these changes in the patient's behaviour and social life imply is that, as hypothesised by the study, there was a movement toward a childlike dependency in this group of adolescents and young adults which required the caregivers to assume the dual roles of providing basic care and social interaction. As a result, caregivers were very likely to report that patients were reliant on others rather than being self-reliant. Since the parents are assuming a previous role when providing basic care, it may not be as distressing for them as it is to provide the social interaction that is usually obtained elsewhere. Parents in this study reported great dissatisfaction with the patients' relationships with their friends, and as suggested by B.D. O'Brien (1987), they experienced extreme distress at seeing their children excluded from the normal activities

CHAPTER SIX - DISCUSSION

The aim of this study was to assess the effects of severe head injury on the family. This was achieved by evaluating which behaviour changes and personality difficulties were present in a sample of brain-damaged adolescents or young adults, and by examining the relationship between these difficulties and the mood disturbance and stress in the primary caregiver. By choosing this age group, the study addressed the need to delineate concerns and outcomes specific to adolescents and young adults.

Furthermore, the study attempted to ascertain whether Lezak's developmental stage model of family adaptation to head injury is accurate for a South African population. In relation to this, the family's coping behaviours, sources of stress, and available support were considered as these could have an important effect on the family's outcome. Findings are discussed with reference to these two major concerns of the study. Limitations of the study are then discussed.

6.1 INTERPRETATION OF THE FINDINGS

6.6.1. WHAT EMOTIONAL, BEHAVIOURAL, AND PERSONALITY DISTURBANCES ARE FOUND IN ADOLESCENTS OR YOUNG ADULTS WITH SEVERE HEAD INJURY, AND WHAT ARE EFFECTS ON THE PRIMARY CAREGIVER?

In this sample of very severely head-injured patients, the most significant finding was in terms of the patients' relationships with others, particularly with their friends. Results of the Bipolar Personality Adjective Scale (BPAS) suggest that both the caregivers and the patients were most likely to report that patients liked company, as would be expected in this age distribution. However, due to the patients' behaviour difficulties, relationships with such patients become very difficult. Patients at 1-8 years post injury were perceived as childish, demanding, emotional, talkative, irresponsible, and lacking motivation. These

placed in a dark room. Particularly with patients with less time since injury, caregivers reported that each day brought something strange and incomprehensible. As reported in the literature, frequent comments by caregivers soon after the injury asked "What should we do?" and "Where shall we take him/her?" There was no information available for either of these questions, yet the families were desperate for such knowledge and support to increase their understanding of their difficulties and to relieve some of their anxieties. As pointed out by one caregiver, families find it difficult to accept that there is physical damage when it cannot actually be seen.

The greatest need for these caregivers was a rehabilitation centre specifically designed to assist people with head injuries, both soon after the injury and in the years following. Caregivers and patients needed time away from one another, and it was thought that a rehabilitation centre could stimulate the patient while the caregiver obtained some respite from caring for the patient. Although there are a number of facilities which worked with handicapped people, the focus is usually not on the mental and behavioural problems associated with brain damage after head injury. As a result, caregivers commented that the professionals in these settings frequently did not actually know how to deal with severe head injury cases.

changes that occurred were not indicative of emotional detachment or a reorientation that provided peace and emotional liberation. Changes, such as permanently staying at home to care for the patient, were typically made to accommodate the patient at the expense of others in the family, particularly the primary caregiver.

5.5.5. THE AVAILABILITY OF SUPPORT

Fifty percent of parents reported that they had not received adequate help from the hospitals and other agencies. Complaints involved a lack of hospital staff to adequately meet the patient's needs and a lack of help from the hospital in placing the patient. Furthermore, complaints about the neurosurgeons' interpersonal manners (reported by 87.5% of caregivers) were noteworthy. They were said to extremely unsupportive, showing little consideration for the patient's family.

The only support group that seemed to be available was Headway which was contacted by 4 patients and their caregivers. This was a source of great relief to some parents because the knowledge that others have been through the same difficulties reduced the isolation. Many parents emphasised the extreme importance of acquiring adequate support. Professional help that was used included occupational and speech therapy, physiotherapy, counselling, and neuropsychology. In some cases, these forms of assistance were very useful for the patient and his/her family. However, some caregivers complained that approaches were not always appropriate for a particular patient. For example, one mother believed that the occupational therapist expected too much from her son and his inability to cope made him feel inadequate and frustrated.

Seventy-five percent of caregivers reported that there was other forms of help which they required but did not receive. One form included having counselling available for the whole family, particularly during the acute phases post injury, when a great deal of shock is experienced. Information to assist caregivers was severely lacking and caregivers commented that there was no manual to tell them what to do so caring for the patient was like being

person post injury as before the injury. In some cases, expectations for improvement were still reasonably high if the time limit on recovery predicted by doctors had not been exceeded.

In terms of past expectations, 3 caregivers reported that their expectations at present were different from earlier. All of these had higher hopes for improvements closer to the time of injury. Similar to findings in the literature, one of these parents found that improvements tended to taper off at one year post injury although some changes had occurred since then. Except in the very acute stages of injury, all caregivers had previously expected great improvements to occur in the patient after the injury. In the acute stage all caregivers were presented with the news that their child would either die or would remain in a persistent vegetative state. The label of "brain-damaged" was particularly frightening for parents, especially when the term was not adequately explained to them. Parents reported that they did not believe the negative prognosis and most (87.5%) expressed anger toward the medical professionals for their inaccuracies. However, in the long term some thought that perhaps a very negative prognosis was preferable to raised false hopes. The finding that relatives resent information with strong negative predictions coincides with that found by Jansen and Friedman (1995) who specifically examined the family's interaction with the medical professionals.

According to Lezak (1986), the caregiver should be able to accept the patient as s/he is without dwelling on how s/he used to be, from 18 months onwards. In the present sample then, all caregivers should have reached this level of functioning. As can be seen in Table 15, however, this does not occur across all subjects. Some subjects reported that they frequently wished the premorbid relationship could be recovered (an activity belonging to Lezak's third stage). Furthermore, some of those that report be able to avoid dwelling on the past, frequently do so consciously, with great effort.

In terms of changes in caregivers' lifestyles since the injury, most reported that their lives were different, as would be expected if they had achieved reorganisation. However, the

5.5.4. EXPECTATIONS OF THE CAREGIVERS

Since the expectations of caregivers are an essential part of Lezak's (1986) framework, an attempt was made to ascertain what the caregivers' expectations were at the various points in time following head injury and how they had changed over time. The level of acceptance of changes in the patient is also very important in terms of Lezak's (1986) stages. Caregivers who have reached the fifth and sixth stage of adaptation should be able to accept the changes in the patient. Furthermore, it is likely that the lives of those caregivers in the last stage will be different from before the injury if they have achieved reorganisation with its emotional , and perhaps physical, detachment from the patient proposed by Lezak. Results over time in these areas are shown below (Table 15).

TABLE 15: CAREGIVERS' EXPECTATIONS, LEVEL OF ACCEPTANCE & LIFE CHANGES

QUESTIONS	TIME SINCE INJURY							
	15	20	22	28	30	38	42	54
Do you expect any improvement in the patient's functioning?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Have you always had these expectations?	Yes	No	Yes	Yes	Yes	Yes	No	No
Are you able to accept the patient as she is?	Yes	Yes	Yes	No	No	Yes	No	Yes
Since the injury, is your life very different?	Partially	Yes	Yes	Partially	Yes	Partially	Partially	Yes

As is shown in the table, only the caregiver at 54 months expects no improvement. This is quite different to Lezak's (1986) conceptualisation which suggests that caregivers' expectations for improvement begin to lessen at approximately 9 months, until at 18 to 24 months they expect little or no change. According to her framework, only three or perhaps four of the present sample should expect improvement in the patient's functioning. Yet, even the subject at 42 months stated that she never gives up hoping for some more improvement although she had realised at 6 months that the patient was not the same

Linked to this concern for safety is the stress of the responsibility of constantly needing to watch over and protect the young adult who acts like a child. One mother's exclamation that "no-one tells you that after coma you are getting a baby back!" clearly indicates the extent of care required by a head-injured individual. It also expresses the extreme degree change that occurs in such patients, which was particularly stressful for a number of the parents. This is in keeping with the literature that reports higher levels of stress associated with greater change in the patient. Also, changes in the patient often involve the strain of social ambiguity since the best way to manage an individual with severe brain damage is not prescribed (Koseullek et al., 1993). Caregivers found inappropriate behaviours embarrassing. One subject revealed her wish that she could give her head-injured child a T-shirt stating "I have had a head injury" so that people could understand her odd behaviours. However, other parents found it irrelevant whether or not others knew about the head injury, since the general population were generally insensitive.

With all the attention required by the patient, some parents (25%) felt that there was insufficient time for activities that were previously important to them. They reported feeling divided between the injured child and their other children, and having little time available for themselves. One mother referred to it as "a balancing act" in which somebody always loses out. The problems in the patient's relationships so frequently reported and so clearly visible in this sample become more understandable in view of these difficulties; with parents feeling responsible for, yet also resentful toward, their injured child; and siblings feeling somewhat resentful of the injured child who receives all the attention.

The fact that the situation in South Africa was in the top seven list of stressors for this sample underlines the importance of studying head injury within specific populations and questions the generalisability of research findings from other populations.

Financial stress was reported with the greatest frequency in the present sample. The significant role played by financial issues in families with head-injured members is understandable considering the astounding medical costs, the numerous services required for recovery and rehabilitation, and the extensive recovery time. Money saved for other purposes were often used in the care of the patient. It was emphasised by the parents that without finances, recovery in the patient is likely to be very negatively affected. A number of caregivers questioned the plight of those unfortunate families who could not afford to care for their loved ones. This is an echo of O'Brien's (1987) comment that if a family is not one of the fortunate 5% of head-injured families who are receiving services, professionals and families must continually fight for services and funding for the remaining 95%. The resulting medico-legal issues were added burden for some caregivers in the present sample.

Concern for the patient's future and safety was also a major stressor. According to Lezak's stages, such worry about the patient's future begins when caregivers begin to realise the extent of change in their head-injured relatives. In the present sample, parents expressed anxiety about their child's possible future career and interpersonal relationships. One parent was concerned that the patient would be left distant from others when friends become more involved in their own lives, with marriage and/or careers. It is likely that these worries are strongly linked to the age or stage of development of the patients with parents expecting adolescents or young adults to be striving towards a successful independent adulthood. Although there is a move toward independence, adolescents and young adults are still dependent on their families of origin for economic sustenance and social outlets (Hatfield & Tolley, 1993). As hypothesised by this study, a total disruption of these hopes is a great source of stress for parents. The issue of safety was raised strongly by one mother who was very concerned because of her head-injured son's childlike and trusting behaviour since the injury. She felt that without her constant supervision, people could easily take advantage of someone who forgets warnings that the world is not always a safe place. Caregivers worried about who would care for the patient if they were ever unable to do so.

TABLE 14: LEVEL & NATURE OF STRESS IN CAREGIVERS

TIME SINCE INJURY (MNTHS)	LEVEL OF STRESS(SCALE:0-6)	MAIN SOURCE	OTHER STRESSORS
15	6	Worry about patient's future/safety	S.A. situation
22	6	Worry about patient's future; Responsibility of caring for patient	Finance
25	5	Less time available	Finance; S.A.situation; Responsibility of caring for patient and others
30	4	Patient's temper	None
38	3	Worry about future	Finance
42	4	Change in patient's personality / behaviour	Finance; Difficult sibling relationships
54	5	Worry about patient's future, especially interpersonally	Finance; Effect the patient has on caregiver's relationship with others

All the above stressors were sorted into 7 different categories of sources of stress. The percentage of the sample which reported each of these categories are shown below.

FIGURE 10: SOURCES OF STRESS IN THE CARE GIVERS

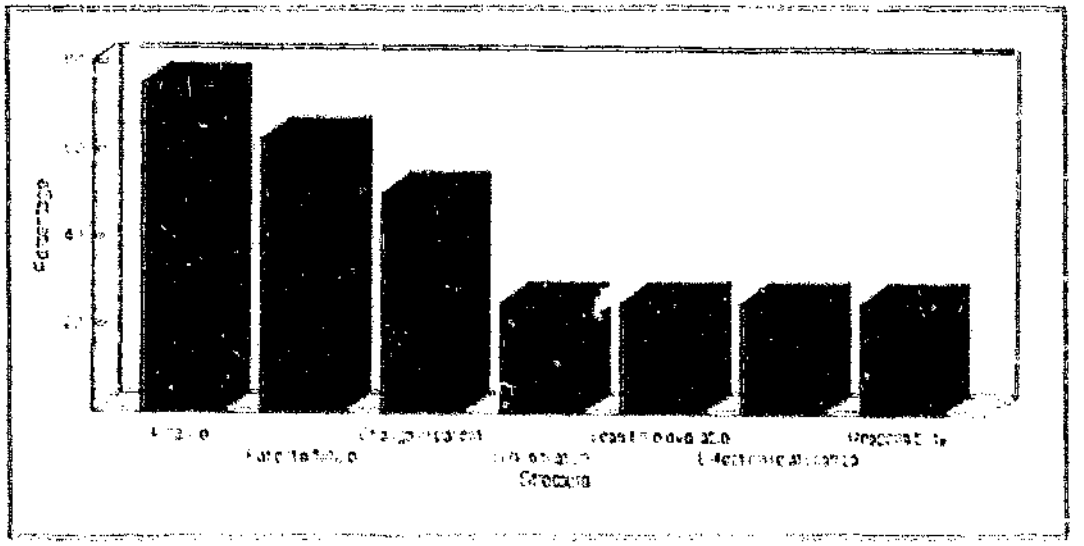
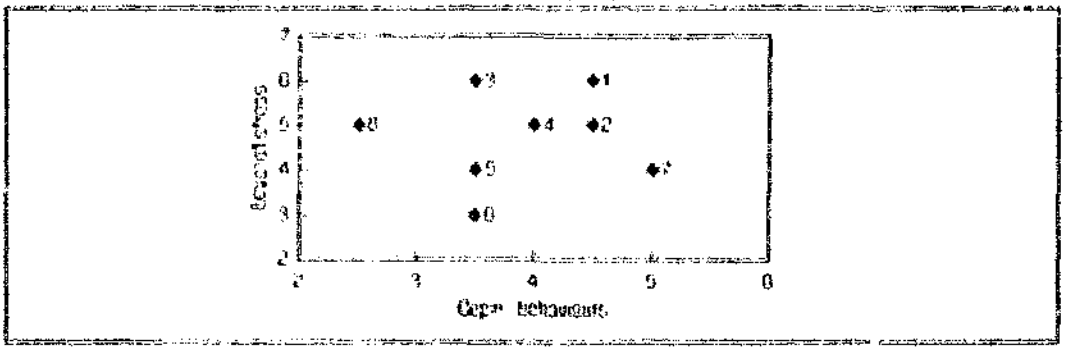


FIGURE 9: COPING BEHAVIOURS AND LEVEL OF STRESS IN THE CAREGIVERS



As can be seen from the graph above, no clear pattern exists between number of coping behaviours and level of stress experienced. In some cases, fewer coping behaviours is linked with severe levels of stress (e.g., subject 8), as would be expected; but the opposite is also true with a high number of coping behaviours linked with severe stress (e.g., subject 2, subject 1). A very similar pattern emerges if POMS scores from the 8 parents are graphed against coping behaviours. The degree of association between POMS scores and the reported level of stress was calculated using Spearman's rank-order correlation. The result of r=0.91 (p<0.01) indicates a very significant relationship between the two measures, giving some credence to the measure of level of stress.

5.5.3. STRESS IN THE CAREGIVERS

Information regarding the level and nature of stress in the relatives of head-injured patients was recorded and is shown overleaf in Table 14. As can be seen in this table, parents of head-injured adolescents or young adults have very similar sources of stress. Some stressors are exclusively a result of the head injury, while others could result in stress under normal circumstances, (e.g., South African situation, work) but are exacerbated by the head injury.

share and talk about one's feelings in general was viewed as positive. The single negative response to this issue came from a father who believed that expression of feelings would not serve any purpose due to the lack of consideration for others within his family.

Flexibility of rules and ways of handling tasks were reported by most parents (62.5%), although 2 (25%) reported that their families has set ways of dealing with issues. In terms of supportiveness within the family, 5 parents (62.5%) received assistance in caring for the patient, all of whom greatly valued such support. Strong family support was emphasised by a number of parents as essential both for their own needs and for the recovery in the patient. One mother believed that a collective strength of the family existed in such times of need. However, one mother felt that she was intruding on others by asking for support and this made her feel dependent.

Other coping behaviours emerged during the assessments of the caregivers that were not directly assessed by the questionnaire. These included beliefs of God or a God-like presence that provides strength with which to deal with the stress, a strong sense of determination (particularly if the patient shares that determination), laughter amidst the sadness, a belief that all things happen for some reason and that one must live with the choices which one is dealt, and the sense of some kind of human strength which emerges in times of great stress.

To test whether coping behaviours do result in reduced levels of stress in the caregiver, the number of current coping behaviours for each subject was calculated and compared to the reported level of stress for that caregiver. Level of stress was given on a scale of 0 to 6, 0 represented no stress and 6 severe stress. If the caregiver had reported that a coping behaviour was evident 'to some extent', 0.5 was added to the number of behaviours continuously displayed. The highest number of coping behaviours possible in this study was 5.

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for, their brain-damaged relative was noteworthy. Serious efforts need to be made to develop rehabilitation centres which cater specifically for head-injured patients and their families.

CHAPTER SEVEN - CONCLUSION

The importance of research on head injury, particularly in young individuals, becomes clearly evident when one considers the substantial economic, social, and personal consequences which can occur as a result of brain damage. The study has shown that individuals with severe head injury are frequently reduced to a state of childlike dependency, being unable to financially support themselves, and lacking the social skills required to function independently.

Although adolescents or young adults undergo a similar series of changes in their behaviours, emotions, and personality to those found in studies with older subjects, a number of issues (e.g., extreme difficultly with peer relationships), appear most prominently in this age group. This outcome emphasises the importance of research that focuses specifically on adolescent issues, as was done in the present study. Research findings from adult populations may not accurately reflect the concerns of other age groups and further studies should include populations with subjects from specific age ranges.

The findings of this study show that Lezak's (1986) developmental stage model does not provide an adequate explanation for, or understanding of, family reactions over time. Adherence to her model would be inappropriate for any one of the families studied, and clinicians should be cautioned against rigidly applying her assumptions to all families. The results are best understood by examining the "person-injury-environment outcome" described by Sbordone (1990), to account for the heterogeneity and individual differences so typically found in head-injured populations. Future researchers and clinicians treating head-injured patients and their families should consider the uniqueness of each subject and situation.

Undeniably, the long-term sequelae of injury have long-term negative impacts on families. Yet, the lack of professional assistance to help these families deal with, and care

Since the biographical questionnaire was constructed by the researcher, it was not possible to establish formal reliability and validity co-efficients. Furthermore, although subjects were assured of anonymity, the presence of the researcher during the completion of the questionnaires may have prevented the caregivers from entirely candid. They may have felt the need to portray their injured child and families in an overly positive light. Also, in some cases, the patient was present during the assessment, which was more likely to result in restricted responses.

optimistic view of future. This may reflect the denial found in the relatives of head-injured patients, yet what has not been previously noted is that this denial may be a function of inaccurate predictions by the medical professionals, rather than being a mechanism that families automatically use to deal with intense distress. This could have important implications for the literature on stress and coping.

In view of such literature, the present study attempted to evaluate the effects on the caregivers' distress of various coping behaviours. It would seem that, for the current sample, these coping behaviours did not reduce family distress. However, as Waaland (1990) proposed, strong faith and church support seemed to serve as a sustaining force for some of the families. More research, with more comprehensive measures of coping, is required. Although no significant findings appeared in the present study, the remarkable human strength visible in the caregivers, needs to be more fully understood.

6.2 LIMITATIONS OF THE STUDY

The sample size was very small due to the extreme difficulties in obtaining subjects that would fulfill the requirements of the study. Also, due to the sensitive nature of the research topic, some subjects refused to participate. This inadequate sample size largely prevented analysis via quantitative statistical procedures. Also, except for the single Coloured family, all participants were White. Thus, the sample was not truly representative of a South African population and this limits the study's generalisability to broad population groups.

Furthermore, when plotting the caregivers' emotions over time in order to test Lezak's (1986) assertions regarding families' adaptation processes, the findings had to be based on only one representative for each point in time. The validity of this method must be questioned. To truly test Lezak's assumptions, a much larger sample is required. Also, a longitudinal study would more accurately reflect family reactions over time than the cross-sectional approach of the present study. Unfortunately, this was unavoidable, due to time constraints.

by the present study. From the findings of this study and those reported in the literature, it would seem that head-injured populations exhibit large individual differences. These must be taken into consideration when attempting to explain findings.

The results therefore suggest that Lezak's (1986) developmental stage model cannot usefully be applied to a South African population. This may be due to the lack of support and rehabilitation facilities reported. Such institutions are severely lacking in South Africa. The extreme difficulties experienced by the researcher in obtaining subjects for the study is reflective of the lack of assistance for head-injured individuals. If an institution for these people was in operation, the researcher may easily have acquired all subjects from such a place. Yet, one must continually ask the question "What becomes of these people?" This is a particularly pertinent question given the extended time since injury examined in this study. The complaint in the literature that long-term rehabilitation has seriously lagged behind acute care facilities needs to be emphasised.

Yet, the lack of information and assistance even in the acute stages is problematic. B.B. O'Brien (1987) perfectly summarises the concerns of the caregivers in the present study: "I had no idea of the magnitude of the problem. And the neurosurgeon made no attempt to begin my education. ... No brochures, no lists of agencies in the area, no names to call. Perhaps they didn't consider [my child] a candidate for rehabilitation: he could not walk, talk, dress, or eat with any semblance of independence. But we had hope! Suppose we had given up" (B.B. O.Brien, 1987, p.422). Indeed, one questions what the outcome for the patients in the present sample would have been without the hope and determination exhibited by the caregivers, particularly when one considers the very pessimistic perspectives of the neurosurgeons. The issue of denial of the patient's deficits by the caregivers is frequently reported in the literature on head-injured families. Peck & Warren (1989) argue that despite more realistic and often negative views presented by the neurosurgeon and neuropsychologist, denial of deficit and hopes for complete recovery can occasionally persist for many years. Yet, in the present study, the prognostic statements by doctors were inaccurate and inappropriate. Because of this initial inaccuracy, subjects may later disbelieve other professionals and have an overly

patient is an important determinant of the caregivers' expectations in Lezak's (1986) model, the general absence of changes over time in the perception of patients found in this study would suggest that family expectations and reactions remain fairly static after 15 months post injury. Expectations did remain static with all caregivers expecting improvement in the patients' functioning, until at 54 months post injury, no further improvement was expected. It would seem that at 54 months post injury, the caregiver has reached some level of reorganisation: no further improvement was expected, acceptance of the patient without dwelling on the premorbid individual was attained, and substantial changes in the caregiver's life had occurred as a result of the injury. These findings are different in terms of the timing of stages hypothesised by Lezak which suggest that neither perceptions nor expectations change after 9 months post injury.

In Lezak's model, caregiver reactions change even though perceptions and expectations of the patient remain unaltered. This pattern was also found in the present sample, with emotions varying quite substantially over time. In most cases, the graphs demonstrating mood disturbances in the present study are not explained by Lezak's model. Her model has particular difficulty explaining increases in mood disturbances for a time post injury as long as 33 months. This suggests that her expectations of recovery within approximately 24 months may be very unrealistic for most families. The present study showed that caregivers were still experiencing significant mood disturbances at 54 months after the injury.

Furthermore, evaluation of whether changes in emotions over time could be explained by Lezak's model was made particularly difficult by the extreme degree of overlap possible between her stages. For example, according to her assertions, a family can remain in stage 3 until 24 months or later, yet the caregiver should also have reached stage 6 by this time, and have been through the fifth stage at 15 months. These are part of the conceptual difficulties with such developmental stage models discussed by Rape et al. (1992). According to these researchers, Lezak's model cannot explain why or predict which families are likely to recover, if any; which are likely to vacillate among the stages; and which are likely to remain entrenched in one stage. This is underscored

clinician's report would not have been possible for all patients, and the type of clinician visited varied greatly across subjects. Thus, a relative's perspective is often the only view available.

In terms of the effects that patient behaviour and personality disturbances had on the caregiver, the study had interesting results. In answer to one of the research questions, patients' personality disturbance were significantly related to mood disturbances in the caregiver. This finding is very much in keeping with the literature. However, a greater change in the patients' personal, interpersonal, and social adjustment did not result in a greater degree of mood disturbance in the caregiver. This is in contrast to most findings reported in the literature that the relative's perception of the symptoms arising from the head injury have an impact on the level of stress experienced. This result may be a function of Hall et al.'s (1994) explanation that the method of measuring caregiver distress may be important. Total mood disturbance, as measured by the Profile of Mood States, may not be comparable to other measures of caregiver outcome, like the level of stress, used by other researchers. However, the very significant relationship between total POMS scores and the level of stress experienced suggests that stress levels in the relative are also not related to changes in the patient's adjustment and social behaviour, in the current study.

6.1.2. IS LEZAK'S (1986) DEVELOPMENTAL STAGE MODEL APPLICABLE TO A SOUTH AFRICAN POPULATION AND WHAT OTHER FACTORS ARE LIKELY TO HAVE AN IMPACT?

Lezak's (1986) model attempts to delineate stages in the evolution of family reactions to a brain-damaged member by linking them to stages in the perceptions of the patient and future expectations. Changes over time form the basis of her model. However, the findings of the present study suggest that the relatives' perceptions of patient behaviour and personality disturbances, and their perceptions of their own mood disturbances, do not change significantly over time. It was only the relationship between socially-expected activities and time since injury that approached significance. Since the perception of the

and Nell's study were, in general, considerably lower than those in the present study. This suggests that more severe injuries are associated with greater personality disturbances, as has been found in the literature. One exception to this finding of greater personality disturbances in the present study, is that both patients and caregivers in Brown and Nell's (1992) study rated the patients as disliking company at both 6 and 12 months. Similarly, Jansen (1988) found that patients with mild and moderate injuries were likely to rate themselves as prone to dislike company at 6 months. These differences from the present study probably reflect the higher age groups included in those studies. Again, it would seem that the age of the head-injured patient has a noteworthy impact on the results.

The lack of substantial difference between caregiver and patient reports suggest that even patients with very severe damage are aware of their deficits to some extent and that various behavioural disturbances may be indirect consequences of brain damage or secondary reactions to their altered mental status (Lezak, 1988). This was underscored by some caregivers who reported that in certain instances the patients knew that they were not performing as well as they could before the injury, and that this resulted in extreme frustration for them. As reported in the KAS-R1, patients had to do things slowly in order to do them correctly. The similarity between patient and caregiver reports also seems to suggest that caregivers are not biased judges because of the stress experienced. Giles and Clark-Wilson (1993) argue that over time, caregivers may be less able to tolerate the disturbances in the patient. This was not shown in the present study, where there was a slight tendency for relatives to report less personality disturbances, and to show less mood disturbances, over time.

While some researchers have questioned the objectivity of using relatives as questionnaire respondents about the patient, if one is to examine the effect of head injury on the caregiver it is imperative to assess the caregiver's view of the patient since it is *their* perspective (however biased) which is likely to determine *their* outcome. Other views, like that of the patients themselves, is also important, yet in some cases, as in the present study, patients were unable to provide the required information due to the extent of the damage or to unavailability. Furthermore, in the present sample, a

	Almost always	Sometimes	Often	Almost never
19. Afraid something terrible is going to happen				
20. Gets nervous easily				
21. Jittery				
22. Worries or frets				
23. Gets sudden fright for no reason				
24. Has bad dreams				
25. Acts as if s/he sees people or things that aren't there				
26. Does strange things without reason				
27. Attempts suicide				
28. Gets angry and breaks things				
29. Talks to himself				
30. Acts as if he has no control over his/her emotions				
31. Laughs or cries at strange times				
32. Has mood changes for no reason				
33. Has temper tantrums				
34. Gets very excited for no reason				
35. Gets very happy for no reason				
36. Acts as if s/he doesn't care about other people's feelings				
37. Thinks only of himself				
38. Shows his feelings				
39. Generous				
40. Thinks people are talking about him/her				
41. Complains of headaches, stomach trouble, other physical ailments				
42. Bossy				
43. Acts as if s/he's suspicious of people				
44. Argues				
45. Gets into fights with people				
46. Is cooperative				
47. Does the opposite of what s/he is asked				
48. Stubborn				
49. Answers when talked to				
50. Curses at people				

KATZ ADJUSTMENT SCALE - RELATIVES' FORM

Caregiver's name ..... Date .....

Please answer all questions, putting a cross (X) on the line which best describes the injured person *as the person was before his/her injury* and a circle (O) in the box which best describes the injured person as *he/she is now.*

If there has been no change following the injury regarding a particular question, please put a circle and a cross in the same box. Do not spend too long on each question; your first impressions are likely to be the most accurate, but please make sure you answer every question indicating how the injured person was before the injury and how he/she is now.

Remember: X = injured person *before* the injury

O = injured person *now*

FORM R1: RELATIVE'S RATINGS OF PATIENT SYMPTOMS AND SOCIAL BEHAVIOUR

	Almost always	Sometimes	Often	Almost never
1. Has trouble sleeping				
2. Gets very self critical, starts to blame him/herself for things				
3. Cries easily				
4. Feels lonely				
5. Acts as if s/he has no interest in things				
6. Is restless				
7. Has periods when s/he can't stop moving or doing something				
8. Just sits				
9. Acts as if s/he doesn't have much energy				
10. Looks worn out				
11. Feelings get hurt easily				
12. Feels that people don't care about him/her				
13. Does the same thing over and over again without reason				
14. Passes out				
15. Gets very sad, blue				
16. Tries too hard				
17. Needs to do things very slowly to do them right				
18. Has strange fears				

SUBJECT CONSENT FORM

FAMILY STAGES OF ADJUSTMENT: CAREGIVERS' EXPERIENCES OF SEVERE HEAD INJURY

I HAVE BEEN FULLY INFORMED AS TO THE PURPOSE OF THE STUDY. IN SIGNING THIS CONSENT FORM, I .....HEREBY AGREE TO PARTICIPATE IN THE ABOVE STUDY. I AGREE TO THE INFORMATION OBTAINED BEING USED FOR RESEARCH PURPOSES. I UNDERSTAND THAT I CAN WITHDRAW FROM THE STUDY AT ANY TIME.

SIGNED: .....

DATE: .....

APPENDIX A - INSTRUMENTS

SUBJECT INFORMATION SHEET

The questionnaires which you are required to fill out will be used to determine the impact of severe head injury on the primary caregiver 1-8 years after the injury. The information will hopefully provide a greater understanding of the nature of the caregiver's responses at this point in time. Feedback of the findings of the study will be made available to participants so that the study can be of benefit to you.

Participation in the study is voluntary. You may refuse to participate or may discontinue participation at any time, without prejudice towards you. All information obtained in the study will be kept confidential.

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SECTION 2

9. What is your home language? .....

10. Which age group do you fit into (mark with an X):

31-40 41-50 51-60 over 60

11. What is the highest level of education that you have achieved?

None Primary school Some high school Matriculated Some university/college

University/college graduate Postgraduate

12. Before the patient's injury, were you working?

Yes No

13. Currently, are you working?

Yes No

If yes, please state your occupation .....

14. Currently, who do you live with?.....

15. What is your relationship to the patient?

Mother Father Other:

5. Before the injury, what was the patient's highest level of education?

None	Primary school	Some high school	Matriculated	Some university/college

6. Currently, what is the patient's highest level of education?

None	Primary school	Some high school	Matriculated	Some university/college	University/college graduate

7. Before the injury, was the patient working?

Part-time	Full-time	Not at all

8. Currently, is the patient working?

Part-time	Full-time	Not at all

BIOGRAPHICAL QUESTIONNAIRE

Caregiver's name ..... **Date**.....

Tel: ( ) .....

SECTION 1

Patient's name ..... **Sex**.....

1. What is the patient's date of birth?

....
Year **Month** **Day**

2. Please indicate, as accurately as possible, the day, month, and year, when the patient was injured.

....
Year **Month** **Day**

3. What was the type of accident (e.g., MVA)? .....

4. Was the patient unconscious or in a coma?

Yes **No** **GCS:**
PTA:

If yes, could you estimate as to the length of time?

Minutes ..... **Hours** ..... **Days** ..... **Months** .....

31. Furious.....	0	1	2	3	4
32. Full of pep.....	0	1	2	3	4
33. Worthless.....	0	1	2	3	4
34. Forgetful.....	0	1	2	3	4
35. Vigorous.....	0	1	2	3	4
36. Uncertain about things..	0	1	2	3	4
37. Bushed.....	0	1	2	3	4

Adapted from "A Shortened Version of the Profile of Mood States (Shacham, 1983).

PROFILE OF MOOD STATES

Caregiver's name ..... Date.....

Below is a list of words that describes feelings people have. Please read each one carefully. Then CIRCLE one number to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY.

The numbers refer to these phrases:

0 = Not at all
1 = A little
2 = Moderately
3 = Quite a bit
4 = Extremely

1. Tense.....	0	1	2	3	4
2. Angry.....	0	1	2	3	4
3. Worn out.....	0	1	2	3	4
4. Unhappy.....	0	1	2	3	4
5. Lively.....	0	1	2	3	4
6. Confused.....	0	1	2	3	4
7. Peeved.....	0	1	2	3	4
8. Sad.....	0	1	2	3	4
9. Active.....	0	1	2	3	4
10. On edge.....	0	1	2	3	4
11. Grouchy.....	0	1	2	3	4
12. Blue.....	0	1	2	3	4
13. Energetic.....	0	1	2	3	4
14. Hopeless.....	0	1	2	3	4
15. Uneasy.....	0	1	2	3	4
16. Restless.....	0	1	2	3	4
17. Unable to concentrate....	0	1	2	3	4
18. Fatigued.....	0	1	2	3	4
19. Annoyed.....	0	1	2	3	4
20. Discouraged.....	0	1	2	3	4
21. Resentful.....	0	1	2	3	4
22. Nervous.....	0	1	2	3	4
23. Miserable.....	0	1	2	3	4
24. Cheerful.....	0	1	2	3	4
25. Bitter.....	0	1	2	3	4
26. Exhausted.....	0	1	2	3	4
27. Anxious.....	0	1	2	3	4
28. Helpless.....	0	1	2	3	4
29. Weary.....	0	1	2	3	4
30. Bewildered.....	0	1	2	3	4

BIPOLAR PERSONALITY ADJECTIVE SCALE

Patient's name ..... Date .....

You are requested to evaluate someone close to you. Here is an example:

Graceful _ _ _ _ _ _ Clumsy

If you consider him/her to be very graceful, tick the line next to the word 'graceful'; if he/she is moderately graceful, tick the second line; and if mildly, then tick the third line. If you consider him/her to be very clumsy, then tick the line next to the word 'clumsy'; if he/she is moderately clumsy, tick the second line; and if mildly, tick the third line. Please complete the following list of descriptive words in a similar manner.

Remembers recent events		Forgets recent events
Remembers remote events		Forgets remote events
Considerate		Inconsiderate
Kind		Cruel
Happy		Unhappy
Reasonable		Unreasonable
Warm		Cold
Rational		Irrational
Calm		Excitable
Likes company		Dislikes company
Cautious		Impulsive
Talkative		Quiet
Energetic		Lifeless
Generous		Mean
Mature		Childish
Charming		Rude
Confident		Hesitant
Enthusiastic		Listless
Sensitive		Insensitive
Intelligent		Unintelligent
Sensible & down to earth		Silly & out of touch
Clear thinking		Confused thinking
Concentrates well		Easily distracted
Relaxed		Tense
Creative		Unimaginative
Attentive		Inattentive
Stable		Changeable
Self-reliant		Relies on others

"A Bipolar Personality Adjective Scale" by C.P. Jansen, 1987, Unpublished procedure.

FORM R5: RELATIVE'S SATISFACTION WITH FREE-TIME ACTIVITIES

	Satisfied with what she does here	Would like to see him/her do more of this	Would like to see him/her do less of this
1. Work in and around the house			
2. Work in the garden or yard			
3. Work on some hobby			
4. Listen to the radio			
5. Watch television			
6. Write letters			
7. Go to the movies			
8. Attend lectures			
9. Attend club, lodge, other meetings			
10. Shop			
11. Take part in community or church work			
12. Bowl or other sports			
13. Play cards or other table games			
14. Take rides			
15. Visit friends			
16. Entertain friends			
17. Sew, crochet or knit			
18. Read			
19. Go to the library			
20. Just sit and think			
21. Take courses at home			
22. Go to school			
23. Other (what?)			

FORM R4: LEVEL OF FREE-TIME ACTIVITIES

	Frequently	Sometimes	Practically never
1. Work in and around the house			
2. Work in the garden or yard			
3. Work on some hobby			
4. Listen to the radio			
5. Watch television			
6. Write letters			
7. Go to the movies			
8. Attend lectures			
9. Attend club, lodge, other meetings			
10. Shop			
11. Take part in community or church work			
12. Bowl or other sports			
13. Play cards or other table games			
14. Take rides			
15. Visit friends			
16. Entertain friends			
17. Sew, crochet or knit			
18. Read			
19. Go to the library			
20. Just sit and think			
21. Take courses at home			
22. Go to school			
23. Other (what?)			

FORM R3: LEVEL OF EXPECTATIONS FOR PERFORMANCE OF SOCIAL ACTIVITIES

	Did not expect him/her to be doing	Expected him/her to be doing some	Expected him/her to be doing regularly
1. Helps with household chores			
2. Visits her/his friends			
3. Visits her/his relatives			
4. Entertain friends at home			
5. Dresses and takes care of her/himself			
6. Helps with family budgeting			
7. Remembers to important things on time			
8. Gets along with family members			
9. Goes to parties and other social activities			
10. Gets along with neighbours			
11. Helps with family shopping			
12. Helps in the care and training of children			
13. Goes to church			
14. Takes up hobbies			
15. Works			
16. Supports the family			

FORM R2: LEVEL OF PERFORMANCE OF SOCIALLY-EXPECTED ACTIVITIES

	Is not doing	Is doing some	Is doing regularly
1. Helps with household chores			
2. Visits her/his friends			
3. Visits her/his relatives			
4. Entertain friends at home			
5. Dresses and takes care of her/himself			
6. Helps with family budgeting			
7. Remembers to important things on time			
8. Gets along with family members			
9. Goes to parties and other social activities			
10. Gets along with neighbours			
11. Helps with family shopping			
12. Helps in the care and training of children			
13. Goes to church			
14. Takes up hobbies			
15. Works			
16. Supports the family			

	Almost always	Sometimes	Often	Almost never
91. Acts as if s/he can't get certain thoughts out of her/his mind				
92. Acts as if s/he can't concentrate on one thing				
93. Acts as if s/he can't make decisions				
94. Talks without making sense				
95. Hard to understand his/her words				
96. Speaks clearly				
97. Refuses to speak at all for periods of time				
98. Speaks so low you cannot hear him/her				
99. Speaks very loudly				
100. Shouts or yells for no reason				
101. Speaks very fast				
102. Speaks very slowly				
103. Acts as if s/he wants to speak but can't				
104. Keeps repeating the same idea				
105. Keeps changing from one subject to another for no reason				
106. Talks too much				
107. Says that people are talking about her/him				
108. Says that people are trying to make her/him do or think things s/he doesn't want to				
109. Talks as if s/he has committed the worst sins				
110. Talks about how angry s/he is at certain people				
111. Talks about people or things s/he's afraid of				
112. Threatens to injure certain people				
113. Threatens to tell people off				
114. Says that s/he is afraid s/he will injure somebody				
115. Says s/he is afraid that he will not be able to control her/himself				
116. Talks about strange things that are going on inside her/his body				
117. Says how bad or useless s/he is				
118. Brags about how good s/he is				
119. Says the same thing over and over again				
120. Complains about people and things in general				
121. Talks about big plans s/he has for the future				
122. Says or acts as if people are after her/him				
123. Says that something terrible is going to happen				
124. Believes in strange things				
125. Talks about suicide				
126. Talks about strange sexual ideas				
127. Gives advice without being asked				

	Almost always	Sometimes	Often	Almost never
51. Deliberately upsets routine				
52. Resentful				
53. Envious of other people				
54. Friendly				
55. Gets annoyed easily				
56. Critical of other people				
57. Pleasant				
58. Gets along well with people				
59. Lies				
60. Gets into trouble with the law				
61. Gets drunk				
63. Is responsible				
64. Doesn't argue (talk) back				
65. Obedient				
66. Shows good judgement				
67. Stays away from people				
68. Takes drugs other than recommended by hospital or clinic				
69. Shy				
70. Quiet				
71. Prefers to be alone				
72. Needs a lot of attention				
73. Behaviour is childish				
74. Acts helpless				
75. Is independent				
76. Moves about very slowly				
77. Moves about in a hurried way				
78. Clumsy; keeps bumping into things or dropping things				
79. Very quick to react to something you say or do				
80. Very slow to react				
81. Gets into peculiar positions				
82. Makes peculiar movements				
83. Hands tremble				
84. Will stay in one position for a long period				
85. Loses track of day, month, or year				
86. Forgets her/his address or other places s/he knows well				
87. Remembers the names of people s/he knows well				
88. Acts as if s/he doesn't know where s/he is				
89. Remembers important things				
90. Acts as if s/he's confused about things; in a daze				

SECTION 5

29. What professional help or support groups have you contacted?

.....

30. Do you feel that you and the patient have received adequate help or care from various hospitals and other agencies?

Yes **No**

If no, please explain .....

32. Is there any other form of help you feel that you or the patient needed but did not receive?

Yes **No**

If yes, please explain .....

SECTION 4

25. Currently, do you expect any improvement in the patient's functioning?

Yes **No**

If yes, please describe .....

26. Since the injury, have you always had these expectations?

Yes **No**

If no, please describe .....

27. Since the injury, do you see the patient as different?

Yes **No**

If yes, are you able to accept the patient as s/he is without dwelling on how s/he used to be?

Yes **No**

28. Since the injury, is your life very different?

Yes **Partially** **No**

If yes or partially, please elaborate.....

20. Are you able to express feelings and frustrations within the family?

Yes Sometimes No

Please describe how this makes you feel .....

21. Do rules and ways of handling tasks change in your family?

Yes Sometimes No

22. Do you receive help from other family members in caring for the patient?

Yes Sometimes No

Please describe how this makes you feel .....

23. Currently, how much stress do you feel because of the changes in the patient since the injury

0 1 2 3 4 5 6

no stress moderate stress severe stress

If it has affected you, please describe the main source of stress .....

24. Currently, are other major stressors in your life?

Yes No

If yes, please describe and indicate their impact on your ability to cope with the patient .....

SECTION 3

16. Since the injury, please describe the patient's relationship

	IMPROVED	REMAINED THE SAME	WORSENED
with mother	.....	.....	.....
with father	.....	.....	.....
with siblings	.....	.....	.....
with partner	.....	.....	.....
with extended family	.....	.....	.....
with friends	.....	.....	.....

17. Before the injury, did family members feel very close to each other?

Yes Sometimes No

18. Since the injury, do family members feel very close to each other?

Yes Sometimes No

19. Before the injury, did you do things together as a family?

Yes Sometimes No

Currently, do you continue to do these things?

Yes Sometimes No