PERCEPTIONS OF FAMILY ENVIRONMENT AMONG SEVERELY HEAD INJURED PATIENTS AND THEIR RELATIVES

BY

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ABSTRACT

This study assessed the perceived family environments of 20 severely head injured patients (post traumatic amnesia, PTA>7 days), 2.5-10 years post injury. Descriptive data, including pretraumatic, injury-related, and postinjury characteristics were presented in order to provide a context in which to evaluate long-term postinjury family environment. Severely head injured patients and their close adult relatives were interviewed, and completed questionnaires independently, in their homes. All subjects had returned to the same family environment in which they had lived immediately prior to injury. Eight were living with both parents, four with a single parent, and eight with their wives.

Persistant symptoms of depression were common to both patients and relatives. The changes in patients reported most frequently by patients and their relatives included impaired memory and concentration, vulnerability to fatigue, and emotional and behavioural changes.

Using the Family Environment Scale, perceived family environments among severely head injured patients and their relatives were compared to those of a normative and a distressed sample. The family environments of severely head injured patients were characterized by significantly more control, less expressiveness and less active-recreational orientation than the normative sample. They reported significantly higher emphasis on cohesion and organization than a sample of distressed families with one dysfunctional member.

Group comparisons were conducted between families of severely head injured husbands and families of severely head injured adult children. Evidence suggested that severely head injured husbands and their wives are more vulnerable to persistant depression than severely injured adult children and their parents. Results concerning the perceived family environments of the two groups indicated that severe head injury is associated with different outcome for the family unit, dependent upon the role of the injured member.

Families of severely head injured adult children were less disrupted and functioned more effectively than families of severely injured husbands. The family environments of severely head injured husbands were

characterized by significantly less cohesion and more conflict than was evident in families of severely head injured adult children. They were also significantly less likely to participate in activities outside the immediate family environment and appeared to be more socially isolated than families where the head injured member was an adult child. Their perceptions of family environment were consistant with a high level of continuing distress and friction. Possible reasons for these differences are discussed.

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DEDICATION

This thesis is gratefully and lovingly dedicated to my parents, Barbara and Donald Douglas.

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Introduction

Head injury is a major health problem. Based on recent population and incidence statistics, it is estimated that 200 - 300 new cases of head injury occur per 100,000 population per year (Anderson, Miller, & Kalsbeek, 1983; Jennett & MacMillan, 1981). Although mortality may be as high as 50% (Langfitt, 1978), improved life support systems and patient management have resulted in ever increasing numbers of long-term survivors (Bond & Brooks, 1976; Jennett, Teasdale, Braakman, Minderhoud, & Knill-Jones, 1976).

The majority of head injured patients are young, active people. Age specific rates for new cases of head injury, the leading cause of which is motor vehicle accidents, peak in the 15 - 24 year age group. Males experience a rate of head injury that is more than twice the rate for females (Anderson et al., 1983). Many of these individuals sustain permanent neurological impairment (Najenson, Mendelson, Schechter, David, Mintz, & Groswasser, 1974; Alexander, 1982). In a large proportion of cases, the family must cope with long lasting problems, frequently with little support (Livingston, Bond, & Brooks, 1985b).

It is generally recognized that sudden serious head injury to a member of any family causes psychological and social changes within the family (Bond, 1975; Bond & Brooks, 1976; Thomsen, 1974, 1984; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Brooks & McKinlay, 1983; Bond, 1983; Oddy, 1984; Brooks, 1984). The present study is concerned with the long-term consequences of severe head injury for patients and their families. It examines the family environment of patients who sustained a severe closed head injury 2-10 years previous to the time of testing.

Until very recently, few studies have investigated the stresses experienced by the relatives of severe head injury victims and the effect that severe head injury to a close relative has on family function. Sufficient information now exists to permit consideration of the following issues:

1. Family response to severe head injury
2. The main features of psychosocial burden as perceived by close relatives of severely head injured patients.

Family Response to Severe Head Injury

For the family, the crisis associated with severe head injury begins immediately post trauma. Characteristically, the family will experience several responses to the crisis. As in the case of other sudden illness or injury; shock, incomprehension, anxiety, denial, anger, guilt and grief may be noted among the relatives of the newly injured individual (Epperson, 1977; Gorman & Anderson, 1982).

Denial.

Denial may prove to be a persistant and particularly pervasive response with head injuries (Romano, 1974; Lezak, 1978; Blazyk, 1983). Romano (1974) studied 13 severely injured patients from the point of admission to periods ranging from 7 months to 4 years post injury. She reports protracted persistance of denial of disability among the patients' families. A tendency to imagine that improvement had occurred when it had not was prevalent. It was her impression that persistance of denial had grave repercussions for both patient and family. Continued denial necessitated certain compromises in daily living. Family life became centred around the injured person. Frequently, this was

accompanied by a decrease in contact with non-family members and, at times, by manifestations of emotional disturbance in those members who might have moved to the point of relinquishing some of their denial.

Unfortunately, Romano provides little information about the patients that she studied or the methods that she used. Consequently, the degree to which her results are representative of families of head injured patients in general remains questionable. There is, however, no doubt that some families maintain a strong belief in the potential for the future recovery of their injured relative, that others fail to recognize, or come to accept, marked negative behaviour changes, and that others have unrealistically high expectations of what their injured relative is able to achieve. In some families these responses are definitely a result of denial which, at times, may prove to be a highly functional and necessary protection against an extremely difficult situation (Brooks, 1984). Bond (1983) reports that most family members have a realistic view of their injured relatives level of disability, between 1 and 2 years after injury.

Disruption of family relationships and existing roles.

When the head injured person returns home, family relationships are frequently strained. One of the most difficult long-term effects of severe trauma on a family system is disruption of existing roles (Lezak, 1978; Cleveland, 1979; Blazyk, 1983). Family members may be forced into predominantly caretaking functions. Consequently, habitual behaviour patterns become subsumed by preoccupation with needs of the injured family member. The goals of the family tend to change or disappear as energy is diverted towards meeting these needs. Normal family function may be disrupted by conflicts over control.

Disruption of existing roles frequently leads to marital discord and may become the basis for separation. Reports of divorce rates for the head injured population vary markedly. Panting and Merry (1972) report a 40% divorce rate in their sample of 10 severely injured subjects. Walker (1972) surveyed the marital status of 146 men who had sustained brain injuries in World War II. He found that only 11%, compared with 25% of the male population of the U.S. at that time, had sought divorce. These figures are

problematic because they were based on a highly heterogeneous sample with respect to severity of injury. In a 10-15 year follow up study, Thomsen (1984) found that 7 of the 9 (77%) subjects who had been married at the time of their accident were divorced. Several factors, including preinjury stability of the relationship, severity of injury, and time elapsed since injury, are likely to be related to the variation in reported divorce rates.

Divorce rate is certainly not the only indicator of satisfaction in marital and family life. It is quite probable that many spouses of disabled persons do not seek divorce because of economic and/or social reasons. Rosenbaum and Najenson (1976) compared the wives of 10 brain injured men with the wives of 10 paraplegics and 10 normal controls. They found that the wives of the brain injured group had a more restricted social life than the wives of the paraplegics. They also showed significantly more symptoms of depression than did the wives of paraplegics and normal controls. The higher levels of depression were associated with behavioural and role shifts in their head injured husbands. These wives had found it necessary to assume increased responsibility for household affairs and complete

responsibilty for child rearing. In many cases, wives had lost their main confiding relationship and marital tension developed.

Few studies have examined their results specifically in terms of the vulnerabilty of different family relationships. Several reports have suggested that marital relationships are less stable than parent-child relationships, when exposed to the consequences of severe head injury (Panting & Merry, 1972; Thomsen, 1974, 1984). Thomsen (1974) reported that the different reactions in spouses and parents were striking, the former expressing only too realistic views and the latter the opposite. Frequently, relationships between injured patients and their children developed badly, resulting in increased stress on the spouse. In her 1984 study, Thomsen commented that father-son relationships became more easily strained than mother-son relationships, when both parents were living with a severely disabled son.

Oddy and Humphrey (1980) reported their findings of a 2-year follow-up of 35 head injured subjects and their relatives. When both patients and relatives were asked to rate how they got on with the family, neither reported poorer relationships than a control group of

patients, who had suffered traumatic injury without injury to the head. Disruption had been reported at the 12 month assessment. Continuing friction was reported between patients and siblings. This was seen as perhaps reflecting a greater willingness, on the part of parents, to admit that this form of friction occurs, while denying that they personally are involved. Nevertheless, sibling relationships may be more vulnerable to this form of stress.

Two recent studies (Livingston, Bond, & Brooks, 1985a, 1985b) have assessed the impact of severe head injury on wives and mothers of patients. Female relatives of male minor and severe head injury victims were interviewed 3, 6 and 12 months after injury. The results showed that there was a measurable emotional and social impact on the relatives of the severely injured subjects. The pattern was one of mood disturbance together with social and role dysfunction in roles performed within the family home. At 3 months, problems were developing in marital relationships and relationships with other cohabiting family members. Difficulties appeared to be circumscribed and had not extended into recreational and occupational activities. Social and leisure activities, functioning at work, as

a parent, and with the extended family, were not impaired. There was no evidence to support the contention of a different pattern of psychosocial morbidity in wives and mothers of severely injured subjects.

At 6 and 12 months postinjury, there continued to be no difference between the patterns of emotional and social dysfunction found in wives and mothers. Social function of the relatives of severely injured patients deteriorated significantly after the 3 month assessment. Poorer role functioning was evident in all roles as time from injury increased.

Emotional dysfunction.

In many cases, the daily burden of living with a severely head injured relative leads to depression. Frequently, family members become depressed when the patient fails to improve and the family are not able to come to terms with the lack of progress. The demands of caring for a severely head injured relative tend to decrease the family's social life. When this is coupled with inappropriate behaviour on the part of the injured relative, isolation, withdrawal and depression seem to be a common response among family members (Thomsen,

1974; Rosenbaum & Najenson, 1976; Lezak, 1978; Oddy, Humphrey, & Uttley, 1978; Blazyk, 1983).

Oddy, Humphrey, and Uttley (1978) interviewed 54 relatives within a month of the patient's accident and again 6 and 12 months later. The proportion of relatives showing significant levels of depression on a depression scale was approximately 25%, compared with 17% reported for the general population. The same group of patients and relatives were followed up 7 years later (Oddy, Coughlin, Tyerman, & Jenkins, 1985). Assessment of emotional disorder amongst the relatives and patients revealed higher incidence in the former, but there was no clear evidence of unusually high incidence in either group. They concluded that most patients and relatives had made some successful adaptation to their altered situation. Bond (1983) states that many families are able to separate emotionally from the disabled person and develop emotional coping strategies between 1 and 2 years after injury.

In a study of patients admitted to a rehabilitation centre, Panting and Merry (1972) found that almost two thirds of the relatives were under stress. Over 30% of the relatives interviewed by

Livingston et al. (1985b) had levels of anxiety likely to be of clinical significance 12 months after injury. This incidence is twice the level of psychiatric dysfunction found in the general population. The persistant psychological malfunctioning shown by the relatives was suggestive of continuing stress. Relatives did not consider that the patient was improving and they perceived a high level of burden for themselves throughout the year.

The Main Causes of Psychosocial Burden as Perceived by Relatives of Severely Head Injured Patients

A number of studies have suggested that mental and personality changes produce more stress for relatives than purely physical disabilities. In a 6-year follow-up of 32 severely injured patients, Fahy, Irving, and Millac (1967) found that few escaped permanent sequelae. Recovery of motor function was generally good. Eventual neurological residua were more easily tolerated by relatives than emotional and behavioural impairment. Panting and Merry (1972) also reported that emotional disturbances caused much more distress in relatives, especially as they tended to persist longer than physical disabilities.

In Thomsen's (1974) study of 50 severely injured subjects, none of the relatives complained of difficulties connected with motor deficits. Nearly all of the relatives complained of changes in the patient's personality and behaviour. Lack of social contact was the greatest subjective burden for the patients, while changes in personality and emotion presented the severest burden to the families. Neuropsychological deficits, especially impaired memory, were also felt to result in a much heavier burden than physical disability.

Ten years later, Thomsen (1984) reviewed this same group of patients. Although several relatives reported gradual improvement in behaviour in the first 5-6 posttraumatic years, no one escaped permanent sequelae. Changes in personality, emotion, and behaviour continued to be the most serious problems from the relatives' point of view. Despite some fluctuations in symptoms, the frequency of complaints made by relatives had not changed positively. Loss of social contact remained the patients' most disabling handicap in daily life. Not only patients, but also families, had become isolated.

In their comprehensive review of 719 patients, Bond and Brooks (1976) found that the burden of the mental changes of a head injured patient on the family, especially alterations in personality, significantly outweigh the effects of physical handicap. The point that it is emotional, and not physical, change in the patient that burdens a relative was also made by Lezak (Lezak, 1978; Lezak, Cosgrove, O'Brien & Wooster, 1980). Five years after injury, behaviour and social disruption was common and affected the patient's ability to get on with other family members.

Investigating the nature and cause of stress on relatives, Oddy, Humphrey, and Uttley (1978) found that the level of stress did not appear to depend on how long the patient had been hospitalized, the degree of disability, or even the severity of the head injury. Personality change and the relative's own perception of the symptoms arising from the head injury emerged as more crucial factors. When asked to describe their major source of stress, relatives referred to aspects of the patients' current condition. Poorly controlled behaviour was the most common complaint.

McKinlay, Brooks, Bond, Martinage, and Marshall (1981) studied the short-term outcome of closed head

injury as reported by the relatives of 55 severely injured persons. The most frequently reported problems were emotional changes, poor memory, and subjective symptoms such as, slowness and tiredness. The mean level of stress, measured on a 7-point rating scale, was the same at 3, 6 and 12 months postinjury. This was consistant with the finding of Oddy et al. (1978) that stress leveled off somewhere between 1 and 6 months. The relationship between the severity of the patient's injury and the degree of stress experienced by the relatives weakened over time. That is, stress in relatives was not a simple reflection of severity of injury. However, there was a relationship between stress experienced by the relatives and certain types of reported problems in the patient. Again, it was found that mental and behavioural changes were associated with significantly increased stress in the relative whereas, physical, speech, and language difficulties were not.

In a later study, Brooks and McKinlay (1983) examined personality change in the same group of subjects by means of bipolar adjectives filled in by a relative of the patient. An increasing number of relatives, approximately 60%, described the patient as

showing personality change in the first year after injury. In those patients described as showing personality change, the changes were in a negative direction with reduced self reliance, reduced sensitivity, and increased irritability being strikingly evident. Between the 3- and 6-month assessments, high burden in the relative became increasingly associated with negative scores on the personality adjectives for the patients.

The reason for the large increase of significant effects over this period was not certain, however, it was considered to be likely that the relatives' toleration of the personality change decreased over time and that this, in turn, led to the increasing association between personality change and burden. The authors report that some of the changes in personality reported by relatives were very marked, and certainly enough to cause distress in the relative and the family in general. They point out that it is very likely that the mechanisms underlying the different types of change vary from patient to patient as a function of the precise pattern of brain damage, the pretraumatic personality characteristics, and the nature of the

social situation in which the patient and the relatives find themselves following injury.

Livingston et al. (1985b) found that the patients' day-to-day functioning was critical for the relatives' well being. The degree of relatives' burden was not predicted by the severity of injury 12 months after injury. The most important predictor of the relatives' emotional and social functioning was the level of subjective complaints expressed by the patients.

Source of Information

It has been suggested that source of information may prove to be an important variable in research concerning psychosocial recovery from severe head injury. Fahy et al. (1967) were the first to report that the accounts of patients and relatives may differ in particular aspects. It was their impression that while patients were sensitive to their difficulties in the fields of intellect, memory, and speech, they seldom acknowledge temperamental changes. Changes in temperament were reported by the relatives as being the most distressing symptoms of the patient's condition. Thomsen (1974) also reported that patients were

particularly prone to failing to admit to the emotional and behavioural changes that their relatives reported.

This issue was further investigated by McKinlay and Brooks (1984). Their data provide further support to the view that there are systematic differences between patients' and relatives' accounts. The picture was similar at 3-, 6- and 12-month follow-up assessments, with agreement between patients and relatives being relatively high (77%) as regards sensory and motor impairments. On questions about memory and concentration, there was an intermediate amount of agreement (63%) and the least amount of agreement (52%) occurred regarding emotional and behavioural changes. These authors conclude that precision about the source of information is important and that differences between the patients' and relatives' view are not random and bear clinical significance.

Summary

The relatively few studies which have examined the effects of severe head injury on the family show some convergence of findings.

Severe head injury has a significant and, in many

cases, longlasting psychological and social impact on the family.

Denial is a common response among close relatives of severely head injured patients. Between 1-2 years post injury, most family members have accepted a realistic view of their injured relative's disability. In some cases, denial may persist beyond this point.

Existing relationships and roles within the family are frequently disrupted. Marital relationships may be more vulnerable to the consequences of severe head injury than other family relationships (e.g. parent-child and sibling relationships).

Family members develop symptoms of emotional disturbance (e.g. depression and anxiety) which appear to be related to continuing stress.

Stress experienced by family members is associated with the emotional, behavioural and personality changes in the patient. Physical disability is more easily tolerated by relatives.

The severely injured patient and the family may become socially isolated as time from injury

increases.

Patient's and relative's accounts of problem areas (e.g. patient symptomatology) may differ significantly.

None of the previous studies concerning the effects of severe head injury on the family have made a global assessment of the social environmental characteristics of these families. Since the immediate family is frequently the major support system for severely head injured persons, potential differences between these families, "normal" families and other distressed families are of clinical as well as theoretical interest. Knowing how family members perceive their own family environments is important in understanding and predicting their behaviour.

More detailed assessment of the perceived environment, social climate and overall functional adequacy of the families of severe head injury victims allows for further delineation of the characteristic changes which may occur in the family unit when the patient returns home. Knowledge about the family environment has implications for designing rehabilitation programmes for patients and relatives.

Such information may help us to understand if, and how, family environment is linked to different patient outcomes.

It is widely accepted that family environment has a crucial influence upon outcome of treatment for children and adults with psychological disorders. Deykin (1972), who studied delinquency and anti-social behaviour, pointed out that family environment may determine both the specific characteristics of a problem and, more importantly, the results that can be achieved by initiating treatment for that problem. Pless and Satterwhite (1973) added that measures of family function would be useful in programme outcome studies because differing types of family function may confound comparisons between treatment and control groups.

In the few studies comparing perceived environment of distressed and normal families, the Family Environment Scale, FES, (Moos & Moos, 1981) has been used most frequently. This scale measures perceived family environment along several dimensions. Previous research using the FES has identified differences between perceived environments of normal families and families with a psychiatric patient (distressed

families). The most consistant finding is that distressed families are seen as having less cohesion and expressiveness and more conflict (Scoresby & Christenson, 1976; White, 1978; Young, Gaynor, Gould, & Stewart, 1979; Spiegel & Wissler, 1983). Such families also tend to be less well organized (Scoresby & Christenson, 1976); less oriented towards independence, achievement, and religious activities (White, 1978; Young et al., 1979); and less concerned with recreational and intellectual pursuits (Janes & Hesselbrock, 1976; Spiegel & Wissler, 1983).

The present study uses the FES to examine the social, environmental and functional characteristics of families of severe head injury victims, who continue to live in the family home, 2-10 years after injury. The family environment is described using the perceptions of adult family members and the head injured patient. It should be noted that the nature of the population used in this study introduces an inherent sampling bias. By the very fact that these families remain intact 2 or more years after injury, it may be assumed that they have made some degree of adaptation to a changed situation. Indeed, these families may represent

the "success stories" in the overall population of families with a severely head injured member.

The study was designed to answer the following questions about the families of severely head injured patients, who continue to live with the family 2-10 years after injury.

1. What is the incidence of depression in patients and their adult relatives?

2a. What symptoms are reported most frequently by patients and their relatives?
2b. Do the accounts of patients and relatives differ?

3. Do the perceived family environments of severely head injured patients differ from normal family environments?

It was hypothesized that the families of severely head injured patients would report more control and organization, and less cohesion, expressiveness, and recreational orientation than normative families. It was also predicted that families of head injured patients would be more incongruent in their perceptions of family environment than normative families.

4. Do the family environments of severely head injured patients differ from those of other distressed families i.e. families with one dysfunctional member?

It was hypothesized that families of severely head injured patients would report more cohesion, organization, and control, and less conflict and recreational orientation than distressed families.

5. Do the family environments of severely head injured husbands differ from the family environments of severely head injured adult children?

It was hypothesized that the premorbid role of the severely head injured patient in the family significantly affects long-term functioning of the family unit.

Where the injured person's role is that of husband, the social climate of the family will be more disturbed than that of families where the patient is in the role of adult child.

It was predicted that families of severely head injured husbands would report less cohesion, expressiveness, and recreational orientation, and more conflict than families of severely head injured children. Furthermore, it was predicted that families

of injured husbands would be more incongruent in their perceptions of family environment than families of injured children.

Method

Subjects

Twenty cases (18 males) with severe closed head injury (CHI) and their adult cohabiting family members constituted the sample for the present study. In closed head injury there is generally no penetration of the dura. The head trauma may result in scalp injury, skull deformation (with or without fracture) and shift of the intracranial contents. The primary mechanism of injury is acceleration/deceleration forces to the head (Levin, Benton, & Grossman, 1982). Patients with penetrating localized injuries were excluded, but all other head injuries, including those with depressed fractures, were admitted to the study. "Severe" injury was defined by a minimum of 2 days posttraumatic amnesia (PTA).

The present sample was drawn from a secondary rehabilitation facility serving western Canada. Head injured patients are referred to this service for evaluation and treatment following discharge from primary facilities in the region. As previous research has indicated that the majority of head injury victims are young (Anderson et al., 1983), participation in the study was limited to patients within the age range

1981). By 1-2 years post injury, recovery has slowed or apparently stopped (Bond & Brooks, 1976; Levin, Grossman, Rose, & Teasdale, 1979; Alexander, 1982). Significant change in outcome category or disability level is not likely to occur after the first 2 years post injury. At the time of assessment, more than 2.5 years had elapsed since the time of injury for all participating subjects. Ten of the subjects were between 2.5 and 5 years postinjury and the remaining ten were 5-10 years post injury. Finally, all subjects were independent with respect to physical mobility i.e. they were not confined to a wheelchair or bed.

Initially, 42 patients were contacted by mail. Of that number, 33 were located and contacted by phone regarding participation in the study. Six patients were no longer living with a close relative and 23 consented to participate in the study. Subsequently, three of these cases were excluded from analysis. One because of previous head injury, one who had a pre-injury history of severe alcoholism, and one whose spouse had a long history of psychiatric disturbance. Of the 20 severely head injured patients included in the study, eight were living with their parents (mother and father), eight

with their spouse (wife), and four with a single parent (two with mother, two with father).

Epidemiological data.

Preaccident demographic data and injury related information were recorded from the files for each participating subject. If data were unavailable in the file, supplementary information was obtained from patient and relative interviews. The following information was collected:

Demographic Variables

1. Sex
2. Age (at time of injury)
3. Marital status (at time of injury)
4. Education (current or completed at time of injury)
5. Employment (at time of injury)
6. Living circumstances (age and relationship of persons living with the patient at the time of injury)

Injury Related Data

1. Cause of injury

   Moving vehicle related

   (passenger/driver/motorcycle/bicycle/pedestrian)

Non moving vehicle related (accident-home/work/sporting; fall/jump; fight/assault)

2. Length of hospitalization - acute care
3. Length of hospitalization - rehabilitation
4. Severity of head injury - Posttraumatic amnesia (PTA)

Materials and Procedure

All data collection for this study took place in the patient's home environment. The head injured subject and his/her close adult relative/s (spouse or parent/s) were involved in this process. Generally, 2 sessions of approximately 3 hours duration were required to complete data collection. In 3 of the 20 cases an extra visit by the researcher was necessary.

At the beginning of the first visit, the rights and requirements of the participants were explained and they were requested to sign a consent form. The initial interview was then completed and the following patient related data were obtained:

Interview data.

1. Age
2. Injury-interview interval
3. Present marital status
4. Present employment
5. Presence of postinjury litigation or compensation
6. Presence of epilepsy
7. Living circumstances (age and relationship of persons currently living with the patient)
8. Hospitalization history (acute care and rehabilitation)

During the remainder of the initial and subsequent sessions, measures of the following variables were collected.

1. Level of disability of the head injury victim.
2. Frequency of symptoms of depression in severe head injury victims and their relatives.
3. Subjective head injury related complaints as perceived by severe head injury victims and their relatives.
4. The characteristics of the family environments of severe head injury victims as perceived by the patients and their relatives.

A summary of the instruments used to measure the above variables is provided in the following sections.

Level of disability.

The Disability Rating Scale (DRS) (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982) was used to assess quantitatively the disability of the severely head injured patients. This scale was developed to follow the progress of severe head injury victims from coma, through different levels of awareness and functioning, to their return to the community. It is a 30 point scale, ranging from 30 = death to 0 = recovery without gross impairment, which provides a shorthand global description of a head injured patient's condition.

The DRS consists of 8 items divided into 4 categories: 1. Arousal and awareness; 2. Cognitive ability to handle self care functions; 3. Physical dependence on others; 4. Psychosocial adaptability for work, housework or school. The method of scoring and definition of each of the 8 items is described in full by Rappaport et al. (1982). A total DRS score is calculated by adding the score for each of the 8 items. These scores have been correlated by the authors with

the following clinical levels of disability: 0 = no disability, 1 = mild, 2-3 = partial, 4-6 = moderate, 7-11 = moderately severe, 12-16 = severe, 17-21 = extremely severe, 22-24 = vegetative state, 25-29 = extreme vegetative state. The total score provides an index of the overall clinical status of a severely head injured patient.

The scale can be completed quickly and inter-rater reliabilities have been demonstrated to be high (0.97-0.98) (Rappaport et al., 1982). In addition to face validity, the scale also has independent validity, since it has been shown to be significantly related to neurophysiological measures of brain dysfunction as reflected in evoked brain potential abnormality scores (Rappaport, Hall, Hopkins, & Cope, 1977).

In the present study, information upon which ratings were based came from personal contact with and observation of the patient. Information on areas which were not observed personally by the researcher was obtained from interviews with family members, in particular, the relative who assumed principal responsibility for the care of the patient. In most cases the DRS was completed after 15-20 minutes

observation of the patient and additional questioning of family members.

Depression.

1. The Wakefield Self-Assessment Depression Inventory (Snaith, Ahmed, Mehta, & Hamilton, 1971) was used to measure symptoms of depression.

This scale was selected because of its brevity (12 items), self-administration format and adequate psychometric properties. Its correlation with the Hamilton Rating Scale is +0.87. At a cut off level of 14-15 points 3% of patients and 7.5% of "normals" are misclassified and the mean scores for male and female patients do not differ significantly.

The scale is largely a modification and shortening of The Zung Self-Rating Depressive Scale (Zung, 1965). It retains the 10 of the 20 Zung scale items identified by Zinkin and Birtchnell (1968) as having occurred more frequently when the test was administered to depressed patients. A further 2 items concerning the experience of anxiety have been included and Zinkin and Birtchnell's modification of Zung's response format has been used (Yes, definitely; Yes, sometimes; No, not much; No, not at all).

Due to the brevity of this scale, a number of the common symptoms associated with depression have been excluded. These include questions concerning hypochondriasis, loss of insight, and change in libido. For the purposes of this study and with respect to the population being considered, the exclusion of such questions was not viewed as a shortcoming. These symptoms often appear as a result of head injury and it may prove erroneous to interpret them primarily as symptoms of depression. Individuals who obtain high scores on this scale are assumed to be suffering from the psychological symptoms of depression, but it should not be assumed that they are suffering from depressive illness as such (Snaith et al., 1971).

Head injured subjects and their adult family members were required to complete this inventory.

Subjective symptoms / complaints.

The Problem Checklist, patient and relative version (PCL-p, PCL-r) constructed by Oddy, Humphrey, and Uttley (1978) was administered to both patients and relatives. A further 5 items were added to the original 37 item list, giving a total of 42 items. The items

relate to personality changes and somatic, sensory, cognitive and psychiatric symptoms.

Patients were asked to complete the checklist by indicating (Yes/No) which symptoms they had experienced during the last 3 months. Relatives indicated which symptoms they believed the patient had suffered from, over the same period. Following completion of the checklist, the subjects were questioned regarding the items answered affirmatively, in order to establish that the problem had either, only occurred since the injury or, had been exacerbated by the injury. Only where this was established was the problem included for analysis.

Family environment.

The Family Environment Scale - FES (Moos & Moos, 1981) was used to measure the social environmental characteristics of the families of severely head injured patients. The Real Form (Form R), which measures people's perceptions of their nuclear family environments was completed independently by the head injured subjects and their adult family members.

The FES contains 90 True/False items which are distributed equally across 10 subscales. The subscales

assess 3 underlying domains or sets of dimensions: the Relationship dimensions, The Personal Growth dimensions, and the System Maintenance dimensions.

The Relationship dimensions are measured by the Cohesion (C), Expressiveness (Exp) and Conflict (Con) subscales. These subscales assess the degree of commitment, help, and support family members provide for one another; the extent to which family members are encouraged to act openly and to express their feelings directly; and the amount of openly expressed anger, aggression, and conflict among family members.

The Personal Growth or goal orientation dimensions are measured by the Independence (Ind), Achievement Orientation (AO), Intellectual Cultural Orientation (ICO), Active Recreational Orientation (ARO), and Moral Religious Emphasis (MRE) subscales. These subscales assess the extent to which family members are assertive, are self sufficient, and make their own decisions; the extent to which activities (such as school and work) are cast into an achievement orientation or competitive framework; the degree of interest in political, social, intellectual, and cultural activities; the extent of participation in

social and recreational activities; and the degree of emphasis on ethical and religious issues and values.

The System Maintenance dimensions are measured by the Organization (Org) and Control (Ctl) subscales. These subscales assess the degree of importance of clear organization and structure in planning family activities and responsibilities; and the extent to which set rules and procedures are used to run family life. A Family Incongruence (Inc) score can also be derived from the FES subscale scores. This score measures the extent of disagreement among family members with regard to their perceptions of family functioning.

In brief, the 10 subscales have adequate internal consistancy (ranging from 0.64 to 0.79), show good 8 week test-retest reliability (ranging from 0.68 to 0.86) and show average subscale intercorrelations around 0.20, indicating that they measure distinct, although similar aspects of family social environments.

Normative data on the Form R subscales have been compiled for normal and distressed families (Moos & Moos, 1981). The FES has been used to describe different types of normal and distressed families in several studies (Moos & Moos, 1976; Scoresby &

Christenson, 1976; White, 1978; Moos, Bromet, Tsu, & Moos, 1979; Young, Gaynor, Gould, & Stewart, 1979; Moos & Fuhr, 1982; Spiegel & Wissler, 1983; Bromet, Ed, & May, 1984; Sines, 1984) and consistant differences between the perceived family environments of normal and distressed families have been identified.

Results

Outline

This chapter contains the primary and supplemental data analyses and results for the study. Data concerning various aspects of the study are presented as follows:

1. Patient characteristics for the entire sample of severely head injured patients.
These include premorbid, injury-related, and postinjury data, including level of disability ratings, for the head injured subjects.
2. Incidence of depression in patients and their close adult relatives.
3. Subjective symptoms reported by patients and their close adult relatives.
4. Family environment profiles are presented, and compared with "normal" and "distressed" family profiles.
5. Comparison of families of severely head injured husbands with families of severely head injured adult children.

Patient Characteristics

Demographic data.

Frequency analyses for the entire sample of severely head injured patients are presented in Appendix A, Tables A-1 - A-4. Eighteen of the twenty subjects were males. At the time of injury, the average age of the subjects was 23.55 years (SD 8.179). The majority of the subjects (65%) fell within the age range of 16-25 years. Just over half the sample (55%) were single at the time of injury. Eleven of the subjects had completed Grade 12 and two subjects had completed University degrees. Eight subjects were full-time students and the remaining twelve subjects were employed at the time of injury.

Injury related data.

Injury related data are summarized in Appendix B, Tables B-1 - B-3. The majority of injuries were a result of moving vehicle related accidents (75%). Eight of the fifteen motor accident victims were passengers, five drivers and two pedestrians. Of the five non moving vehicle related accidents four were work related and one was a result of assault. Length of acute care

hospitalization ranged from 1 week to 4 months. Six subjects were not transferred to an inpatient rehabilitation centre. For the remaining 14 subjects, length of inpatient rehabilitation ranged from 3 weeks to 7 months. Based on length of PTA, all subjects sustained severe head injuries (PTA>7 days).

Interview data.

Data obtained during the initial interview are summarized in Appendix C, Tables C-1 - C-6. For all subjects, a minimum of 2 years had elapsed since the time of injury. Fifty percent were less than 5 years post injury and the remaining subjects were 5-10 years post injury. At the time of testing, the average age of the sample was 28.1 years (SD 9.878). Sixty-five percent fell within the age range of 18-30 years and all the subjects were 18 years or older. Only one subject had undergone a change in marital status and had been separated approximately 1 year post injury. All subjects had returned to the same family environment in which they had lived immediately prior to the accident. Eight were living with both parents, four with a single parent and eight with their wives.

Of the 12 subjects who had been employed at the time of injury, only two were currently holding full-time jobs. In both cases, the work that the subject had returned to was described as less demanding than preinjury employment. Sixty percent of the sample were unemployed at the time of interview. Two subjects were working in part-time jobs and four had returned to full-time study. Litigation/compensation proceedings had been completed for 14 of the 20 cases. The remaining six were awaiting settlement at the time of testing. Two subjects were being treated for seizure disorders and seven had received treatment in the past.

Level of disability.

Disability ratings for the subjects on the Disability Rating Scale (DRS) are summarized in Table 1. No subject was impaired on the items of arousal, awareness and responsivity. Five subjects showed evidence of partial impairment on Category 2: Cognitive ability to handle self-care functions. These subjects needed to be reminded or supervised with respect to completion of activities of daily living. No subject was markedly physically dependent. Eight subjects were physically independent and five were physically

Table 1

Frequency Analysis of Level of Disability (DRS ratings)

(N=20)

Category	Rating	Absolute Frequency	Relative Frequency (%)
1. Arousal.	No impairment	20	100
2. Cognitive ability for self care.	No impairment	15	75
	Partial	5	25
3. Physical dependence on others.	Independent	8	40
	Special environment	5	25
	Dependent	7	35
4. Employability.	Restricted	8	40
	Non competitive	12	60
Total Score	Mild disability	7	35
	Partial	5	25
	Moderate	8	40

independent in a modified environment. Seven subjects required limited assistance i.e. their physical disability would have necessitated assistance from a nonresident rather than live in helper.

The fourth category rates the subject's employability. It reflects in a global way the severity primarily of cognitive, but also physical, disabilities that affect the individual's ability to compete and to undertake useful work in the job market, or to carry out household responsibilities, or responsibilities as a student. Restricted employability was common to all subjects. In all cases, the restriction was primarily a result of cognitive or behavioural, rather than physical, dysfunction. Twelve of the subjects were rated as being noncompetitive in the job market. The remaining eight were rated as competitive within selected and restricted fields of employment.

From their total scores on the DRS, 7 subjects were rated as being mildly disabled, five partially and eight moderately disabled.

Incidence of Depression

Patients.

Frequency analysis of the incidence of depression for the severely head injured patients is presented in Table 2. Eleven (55%) of the severely head injured subjects were classified as showing significant symptoms of depression on the Wakefield Self-Assessment Depression Inventory. Seven of the eight husbands and four of the twelve children were classified as depressed. Two of the children were living with both parents and two with a single parent.

Relatives.

Frequency analysis of the incidence of depression for the relatives is presented in Table 3. Eleven (39%) of the relatives participating in the study were classified as showing significant symptoms of depression on the Wakefield Self-Assessment Depression Inventory. All but one of the wives were classified as depressed. Of the four parents classified as depressed, two were single parents and the remaining two were the parents of one patient.

Table 2

Frequency Analysis of Incidence of Depression in Severely Head Injured Subjects

	n	Absolute Frequency	Relative Frequency (%)
Head injured husbands	8	7	87.5
Head injured adult children	12	4	33.3
Total Sample	20	11	55.0

Table 3

Frequency Analysis of Incidence of Depression in Relatives of Severely Head Injured Patients

	n	Absolute Frequency	Relative Frequency (%)
Wives	8	7	87.5
Mothers	10	2	20.0
Fathers	10	2	20.0
Total Sample	28	11	39.3

Subjective Symptoms

The Problem Checklist elicited one or more complaints in all but one of the head injured patients. Half of the patients mentioned more than 10 symptoms. All of the relatives who had assumed principal caretaking responsibility for the head injured family member reported several problems. More than 10 symptoms were reported by 80% of the relatives interviewed (See Table 4).

The mean number of symptoms reported by patients and relatives is presented in Table 5. There was little difference between the number of symptoms reported by head injured husbands and their wives. All head injured children reported fewer symptoms than were perceived by their parents. There was very little difference between the number of symptoms reported by mothers and fathers.

The symptoms reported most frequently by patients and relatives are shown in Table 6. Impaired memory and concentration, and vulnerability to fatigue are the most frequent, persistant problems reported by both patients and relatives. Emotional and behavioural changes constitute the majority of the remaining complaints. Motor incoordination was the only frequent physical complaint made by both patients and relatives.

Table 4

Number of Subjective Symptoms Reported by Patients and Principal Caretaking Relatives

(N=20)

No. of Symptoms	Patients	Relatives
0	1	0
1-5	5	1
6-10	0	1
11-20	4	8
21-30	8	9
31-40	2	1

Table 5

Mean Number of Symptoms Reported by Patients and Relatives

Patients		Relatives		
Children	Husbands	Mothers	Fathers	Wives
10.13	22.88	17.63	15.38	22.63

16-40 years at the time of injury. In addition, this age range was introduced to control for differences in lifestyle associated with the aging process.

Individuals with a preinjury history of alcoholism, drug abuse, and neurological or psychiatric disorders, were excluded from the study. No participating subject had suffered an earlier head injury involving loss of consciousness. All subjects were currently living with a close relative (spouse or parent/s) with whom they had lived prior to the accident.

The present study is concerned with the long-term consequences of severe head injury for patients and their close adult relatives. A minimum 2 year injury-assessment interval was introduced to control for differences associated with changing disability level in participating subjects. Investigations of the outcome of injury for severely head injured patients have shown that more than 90% reach their final level of disability/outcome category within 6 months of injury (Jennett, Snoek, Bond, & Brooks, 1981). Only 5% of severely injured patients who are followed up over 18 months, improve sufficiently after 12 months to reach a better category of recovery (Jennett et al.,

Table 6

Symptoms Most Frequently Reported by Patients and Relatives

(N=20).

Symptoms Reported by Patients	Absolute Frequency	Relative Frequency (%)
1. Trouble remembering	17	85
2. Difficulty concentrating	14	70
3. Fatigue	14	70
4. Feels anxious and tense	13	65
5. Motor incoordination	13	65
6. Feels misunderstood	12	60
7. Apathy	11	55
8. Excessive talking	11	55
9. Often restless	11	55
10. Often impatient	11	55
Symptoms Reported by Relatives		
1. Trouble remembering	19	95
2. Fatigue	19	95
3. Difficulty concentrating	16	80
4. Often impatient	16	80
5. Difficulty keeping friends	16	80
6. Childish behaviour	15	75
7. Often restless	15	75
8. Motor incoordination	14	70
9. Loses temper	13	65
10. Often irritable	13	65

One of the aims of this study was to ascertain whether systematic differences between patients' and relatives' accounts of problems continue to exist more than 2 years after injury. Research has indicated that patients are particularly prone to failing to admit to emotional and behavioural problems which relatives report. Patients are also less likely to report cognitive problems (e.g. memory impairment) than are relatives. In order to measure agreement between patients' and relatives' reports, cross tabulations with patients' self reports and relatives' reports of symptoms were conducted. The results are presented in Table 7.

These data indicate that, more than 2 years after injury, agreement between patients and relatives is generally high regarding cognitive impairments. On questions about emotional and behavioural changes there is an intermediate amount of agreement. The least amount of agreement is on the ablity to make and maintain social relationships.

Table 7

A Cross Tabulation of Patients' Self-Reports with Relatives' Reports of Changes in the Patients

Cognitive Change

	Impaired Memory Relatives' View YES	 NO	Impaired Concentration Relatives' View YES	 NO
Patients' View YES	17	0	12	2
NO	2	1	4	2
	90% Agreement		70% Agreement	

Emotional - Behavioural Change

	Bad Temper Relatives' View YES	 NO	Anxiety Relatives' View YES	 NO
Patients' View YES	10	0	9	4
NO	5	5	3	4
	75% Agreement		65% Agreement	

Social Change

	Difficulty Making Friends Relatives' View YES	 NO	Difficulty Keeping Friends Relatives' View YES	 NO
Patients' View YES	2	5	10	2
NO	11	2	6	2
	20% Agreement		60% Agreement	

Family Environment

The present study addressed three issues concerning the family environments of severely head injured patients.

1. Do the family environments of severely head injured patients, 2-10 years after injury, differ from normal family environments?

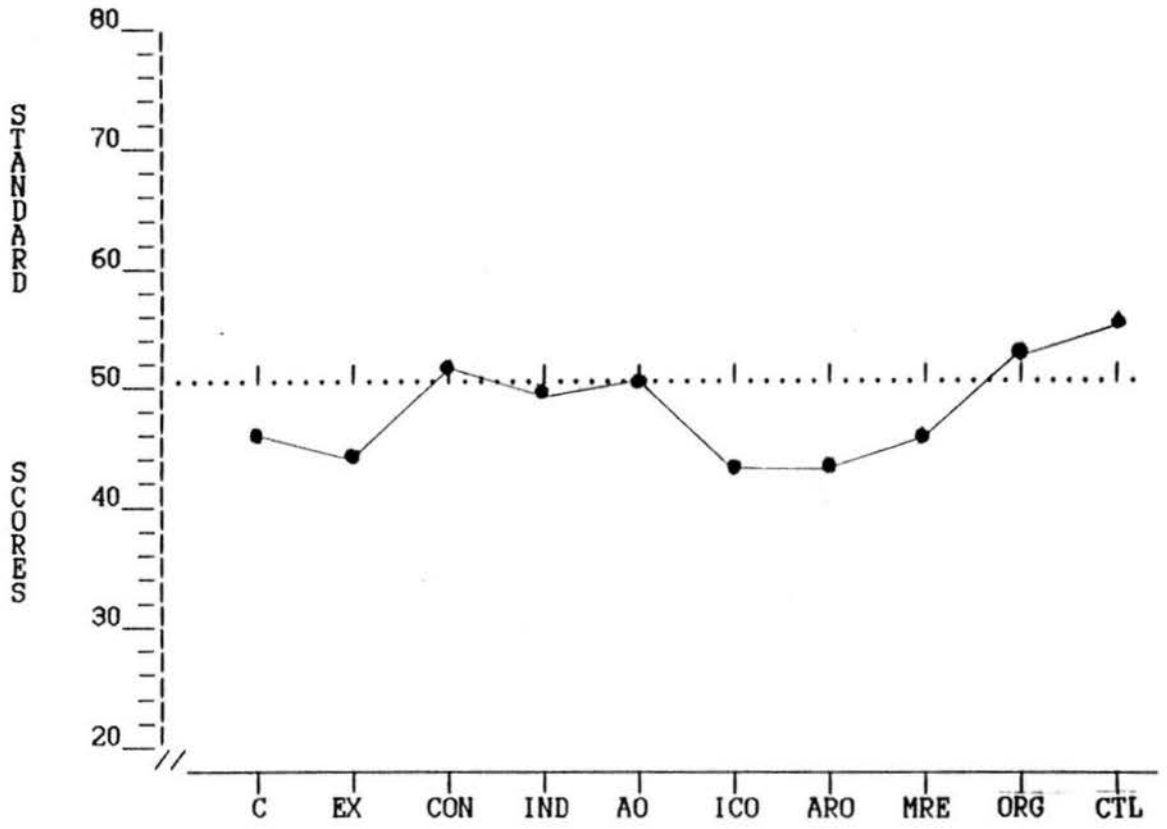
Hypothesis. Families of head injured patients report more control and organization, and less cohesion, expressiveness, and recreational orientation than normative families.

Figure 1 shows the FES (mean standard score) profile for the families of severely head injured patients. On the whole the FES scores for the families of head injured patients are within 1 SD of the mean. Compared to the normative sample (mean of 50), the families of head injured patients are less positive in their evaluation of the relationship and personal growth dimensions and perceive more emphasis on the system maintenance dimension.

Families of head injured patients do report more control and organization and perceive their family environments as being less cohesive, expressive, and

Figure 1

FES Standard Score Profile of Families of Severly Head Injured Patients



C - Cohesion
EX - Expressiveness
CON - Conflict
IND - Independence
AO - Achievement Orientation
ICO - Intellectual-Cultural Orientation
ARO - Active Recreational Orientation
MRE - Moral Religious Emphasis
ORG - Organization
CTL - Control

recreationally oriented than normative families. T-tests of sample versus population means were performed on these five scales to test the significance of the hypothesized differences. The results are presented in Table 8.

Using a significance level of 0.05, families of severely head injured patients differ significantly from normative families on the control, expressiveness, and active-recreational scales. Emphasis on the control scale indicates that set rules and procedures are used in the family environments of head injured patients to a significantly greater extent than within normal family environments. Lower levels of expressiveness and recreational orientation are associated with diminished open communication between family members and a tendency to participate less in social and recreational activities, when compared to normal families. No statistically significant difference was found on the cohesion and organization scales.

Table 8

Hypothesized Differences Between Families of Severely Head Injured Patients and Normal Families

(df = 19)

	FES Scale	t ratio	p value	standard error
	Cohesion (C)	-1.496	0.148	.481
*	Expressiveness (Ex)	-2.594	0.017	.318
*	Active-Recreation Orientation (ARO)	-2.624	0.016	.471
	Organization (Org)	.964	0.349	.360
**	Control (Ctl)	3.392	0.003	.317

Incongruence in perceptions.

Hypothesis. Families of severely head injured patients are more incongruent in their perceptions of family environment than normal families.

The mean incongruence scores for families of head injured patients and normal families are presented in Table 9. The degree of incongruence in patient families is half a standard deviation above the mean for the normative sample. This difference is not significant. In fact, the overall correlation between the relatives' and patients' perceptions of family environment was high (r = .853).

Figure 2 shows the FES (mean standard score) profiles for patients and relatives. In general, the head injured patient perceives the family as less cohesive, controlled, and culturally oriented and reports a higher level of independent activity than do other family members.

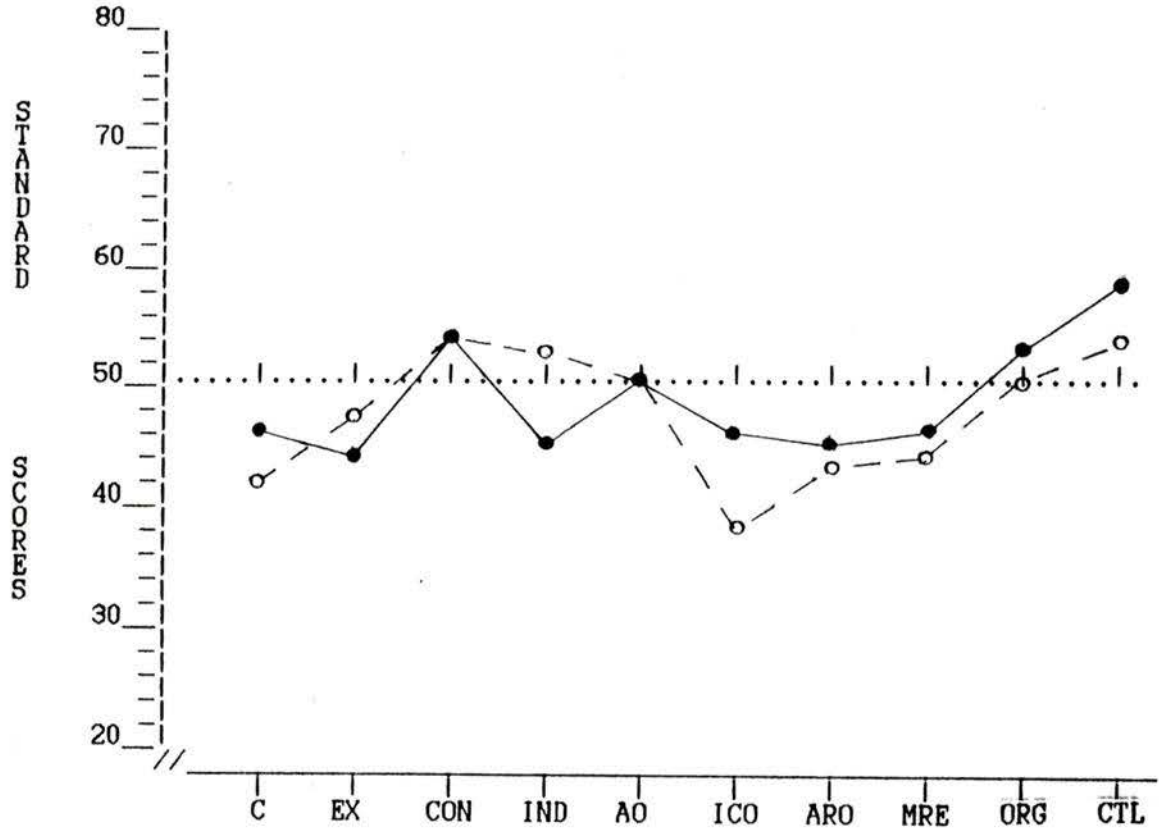
Table 9

FES Family Incongruence Scores

	Patient Families	Normal Families
Raw Score	17.93	15.34
Standard Score	55	50

Figure 2

FES Standard Score Profiles of Severely Head Injured Patients and Their Relatives



C - Cohesion
EX - Expressiveness
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IND - Independence
AO - Achievement Orientation
ICO - Intellectual-Cultural Orientation
ARO - Active Recreational Orientation
MRE - Moral Religious Emphasis
ORG - Organization
CTL - Control

2. Do the family environments of severely head injured patients more than 2 years after injury differ from those of other distressed families (families with one dysfunctional member)?

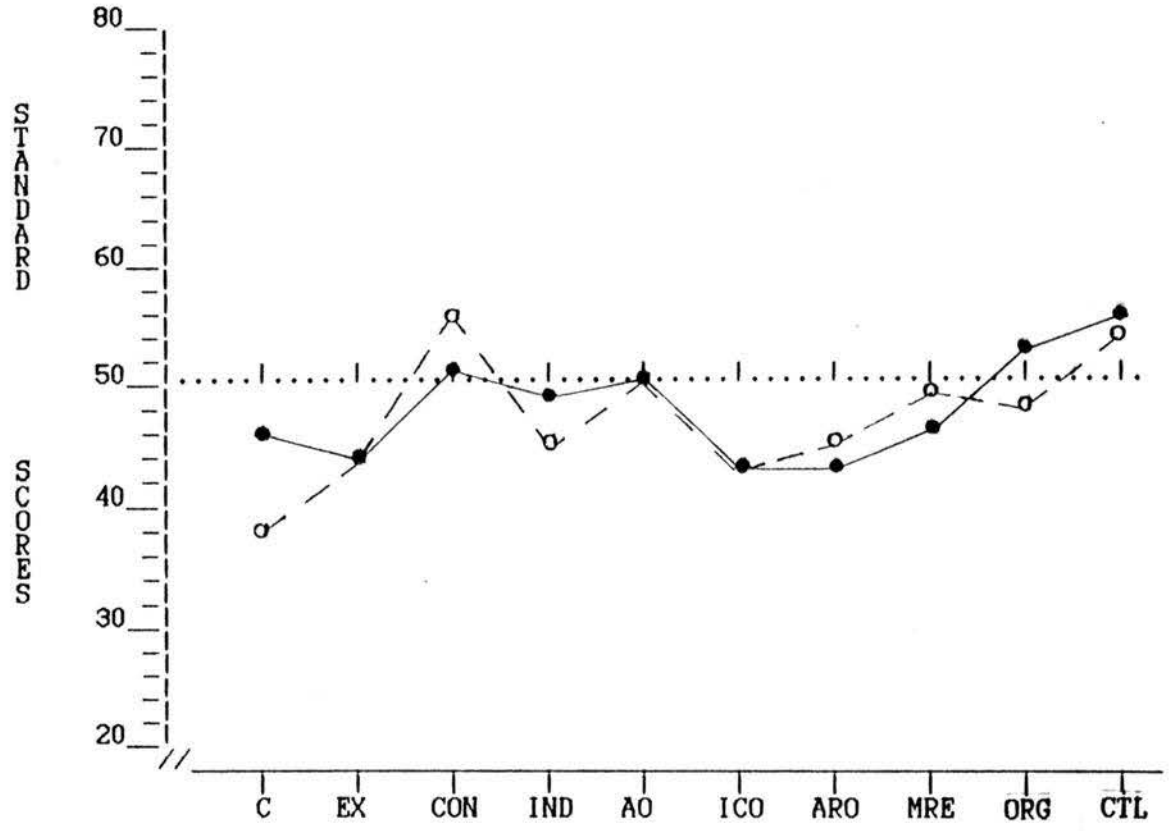
Hypothesis. Families of head injured patients report more cohesion, organization, and control, and less conflict and recreational orientation than other distressed families.

Figure 3 shows the FES (mean standard score) profiles of families with a severely head injured member and a sample of distressed families. Overall, there appears to be few major differences between families of severely head injured patients and distressed families. Families of head injured patients report more emphasis on system maintenance dimensions, more cohesion and independence and less conflict. T-tests were performed to test the significance of the hypothesized differences on the cohesion, organization, control, conflict, and recreational scales. The results are shown in Table 10.

The hypothesized differences on the cohesion and organization scales are statistically significant at the $p < 0.05$ level. There is a trend towards more cohesion and emphasis on organization in families of

Figure 3

FES Standard Score Profiles of Distressed Families and Families of Severely Head Injured Patients



●——● Families of Head Injured Patients

o– –o Distressed Families

C - Cohesion
EX - Expressiveness
CON - Conflict
IND - Independence
AO - Achievement Orientation
ICO - Intellectual-Cultural Orientation
ARO - Active Recreational Orientation
MRE - Moral Religious Emphasis
ORG - Organization
CTL - Control

Table 10

Hypothesized Differences Between Families of Severely Head Injured Patients and Distressed Families

(df = 19)

FES Scale	t ratio	p value	standard error
* Cohesion (C)	1.789	0.043	.481
* Organization (Org)	1.936	0.046	.360
Control (Ctl)	1.814	0.083	.317
Conflict (Con)	-1.036	0.175	.464
Active-Recreation Orientation (ARO)	-0.371	0.675	.471

head injured patients when compared to other distressed families. They perceive a higher degree of support between family members and place more importance on organization, structure, and planning within the family environment than do other distressed families.

3. Does the role of the severely head injured patient in the family significantly effect long-term functioning of the family unit?

Hypothesis. Families of head injured husbands (HIHb) report less cohesion, expressiveness, and recreational orientation, and more conflict than families of head injured adult children (HICh).

Group comparisons.

Table 11 summarizes the descriptive information for both groups. Group 1 (HIHb) comprises families where the role of the head injured patient is that of husband. In Group 2 (HICh), the head injured patient is an adult child living with both parents. Single parent families are not included because the literature suggests that there are significant differences associated with single parent family environments (Moos & Moos, 1981).

Table 11

Descriptive Characteristics of Groups

	Group 1 (HIHb)	Group 2 (HICh)
n	8	8
No. of Males	8	8
Mean Age at Injury(yrs)	32	18.25
Mean Age at Assessment(yrs)	38.63	21.38
Mean Injury/Assess Interval(yrs)	6.38	3.75
Disability Rating:Mean	2.50	3.13
Range	1 - 5	1 - 4
Mean Family Size	3.50	3.50
Mean No. Symptoms-Patients	22.80	10.13
Mean No. Symptoms-Relatives	22.63	17.63

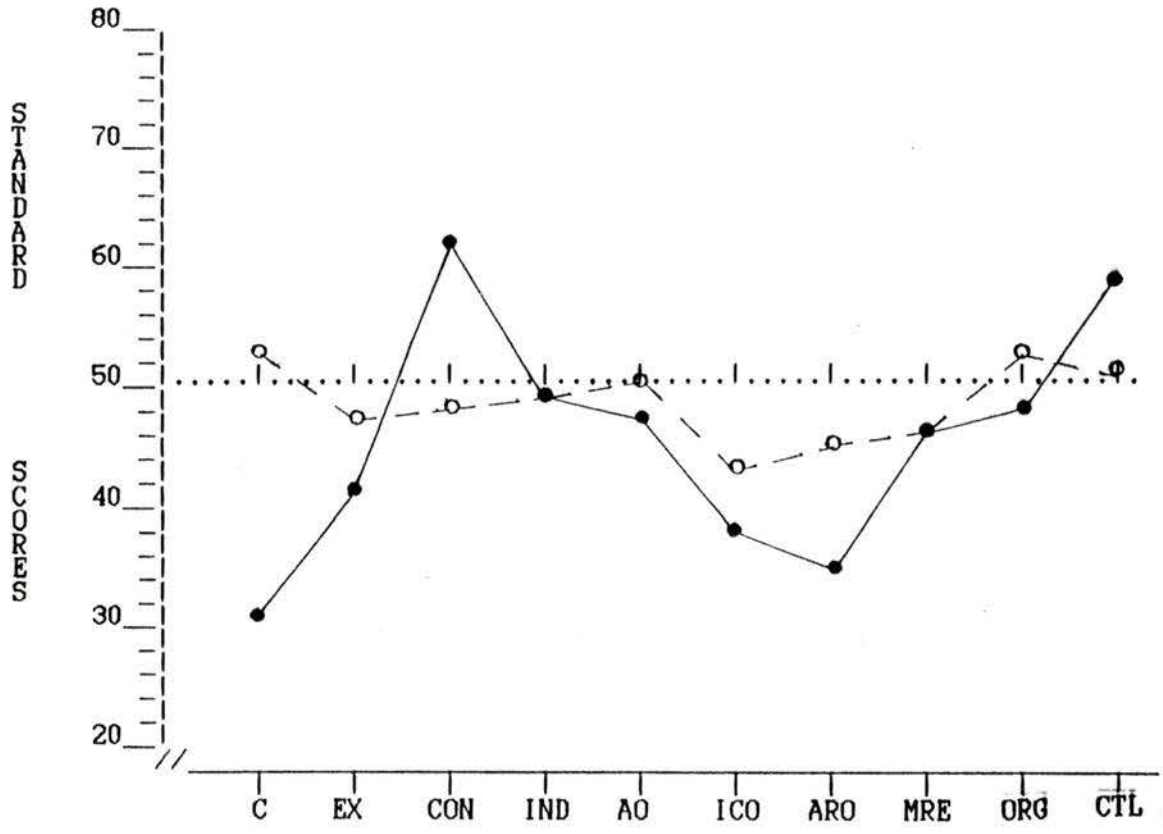
(HIHb = severely head injured husbands)
(HICh = severely head injured adult children)

The two groups are clearly not matched on several of the variables (age at time of injury, assessment-injury interval and number of symptoms reported by the patient) listed in Table 11. On the remaining variables, the two groups are similar.

Figure 4 shows the FES (mean standard score) profiles for Group 1 (HIHb) and Group 2 (HICh). Some striking differences exist between the two groups. Families of head injured husbands report very low cohesion (2 SD's below the mean), low expressiveness (1 SD below the mean) and high conflict (> 1 SD above the mean). In contrast, families of head injured adult children report average or near average emphasis on these 3 scales of the relationship dimension. Group 1 (HIHb) families show less emphasis than Group 2 (HICh) families on all but one (moral-religious) of the personal growth scales. Of these scales, recreational orientation is particularly low falling below 1 SD of the mean. Finally, families of head injured husbands perceive a higher level of control in the family environment than do families of head injured adult children.

Figure 4

FES Standard Score Profiles of Families of Severely Head Injured Husbands and Families of Severely Head Injured Adult Children



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T-tests of independent sample means were performed to test the significance of the hypothesized differences. The results are presented in Table 12. Before completing these tests homogeneity of variance was tested for using the F test. The F test criterion ($F(7,7) < .01$) was met and small sample, pooled or weighted estimate of error was used.

The results show that families of severely head injured husbands report significantly more conflict and less cohesion than families of severely head injured adult children. These families also tend to participate less in social and recreational activities. The two groups do not differ significantly with respect to expressiveness.

Table 12

Hypothesized Differences Between Families of Severely Head Injured Husbands and Families of Severely Head Injured Adult Children

(df = 14)

FES Scale	t ratio	p value	standard error
** Cohesion (C)	-3.830	0.002	.793
Expressiveness (Ex)	-0.811	0.436	.767
* Active-Recreation Orientation (ARO)	-2.168	0.046	.796
** Conflict (Con)	3.503	0.003	.750

Incongruence in perceptions.

Hypothesis. Families of severely head injured husbands are more incongruent in their perception of family function than families of severely head injured adult children.

Figure 5 shows the FES (mean standard score) profiles for the head injured husbands and their wives in Group 1 families. The perceptions of head injured husbands and their wives differ markedly on the cohesion, expressiveness, conflict (relationship dimensions), independence, and control scales. Wives perceive little support in the family environment and little opportunity to express their feelings openly. They report a great deal more anger, aggression, and conflict among family members. Their low score on the independence scale indicates that they perceive family members as being minimally self sufficient and able to make decisions on their own. Scores on the other personal growth scales are low, particularly the two scales (ICO & ARO) which measure participation in activities outside the home environment. The use of set rules and procedure to run family life is emphasized on the system maintenance dimensions.

The head injured husbands' profile shows below average cohesion and expressiveness and above average conflict. Nevertheless, when compared with their wives' perceptions, husbands show more positive perceptions on the relationship scales. Husbands perceive family members as being a great deal more self sufficient than do their wives. Husbands and wives agree that the family participates minimally in activities outside the immediate family environment. Less emphasis is placed on organization and control by the husbands.

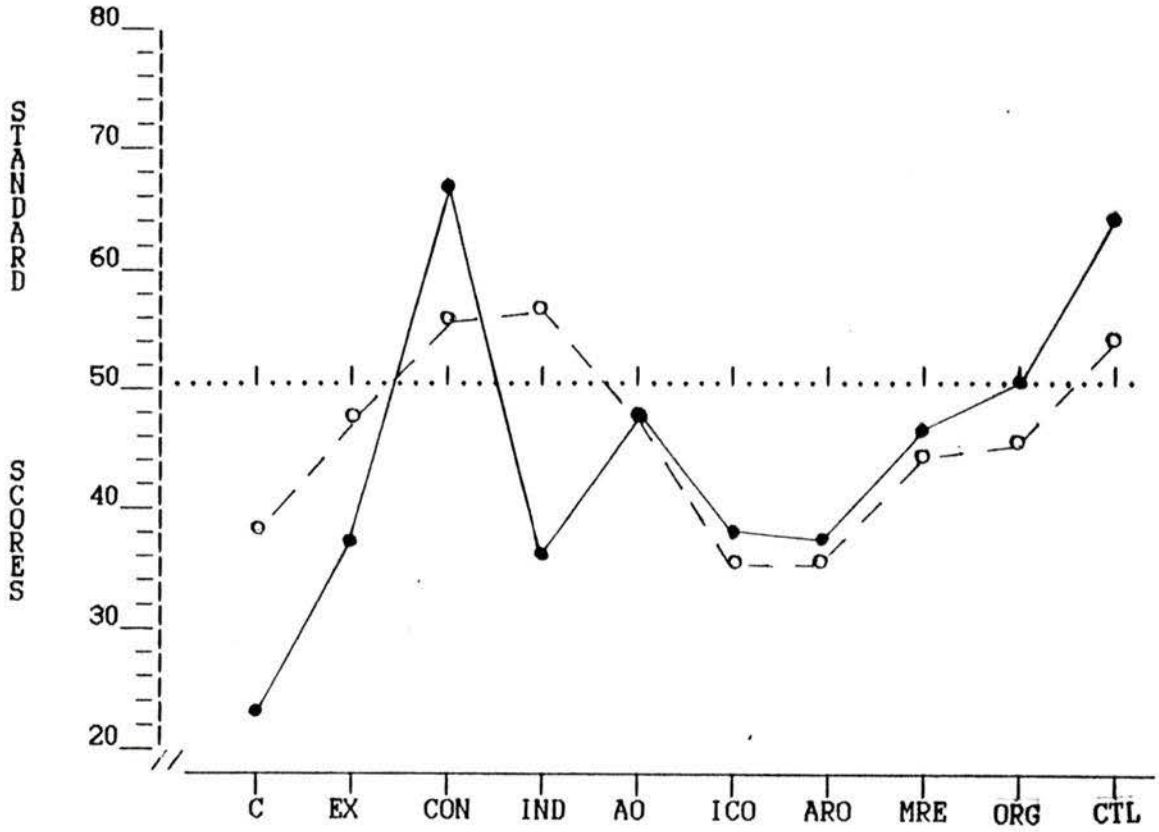
Figure 6 shows the FES (mean standard score) profiles for the head injured adult children and their mothers and fathers in Group 2 families. Parents of head injured children perceive their family environments as being particularly cohesive (1 SD above the mean). In contrast, the head injured member of the family perceives the family as being much less supportive (1 SD below the mean). There is general agreement between parents and their head injured adult children on the remaining scales. Mothers and fathers have extremely similar views of their family environments ($r = .932$).

The mean family incongruence scores for both family groups are presented in Table 13. Mean

correlations between patients' and relatives' perceptions are shown in Table 14. Overall, family incongruence scores for families of head injured husbands are slightly higher than those of families of head injured children. Neither group is more than 1 SD above the mean. Correlations between head injured husbands and their wives are lower than those of head injured children and their parents. Perceptions of male head injured children are more highly correlated with fathers' perceptions than with mothers' perceptions of family environment.

Figure 5

FES Standard Score Profiles of Severely Head Injured Husbands and Their Wives



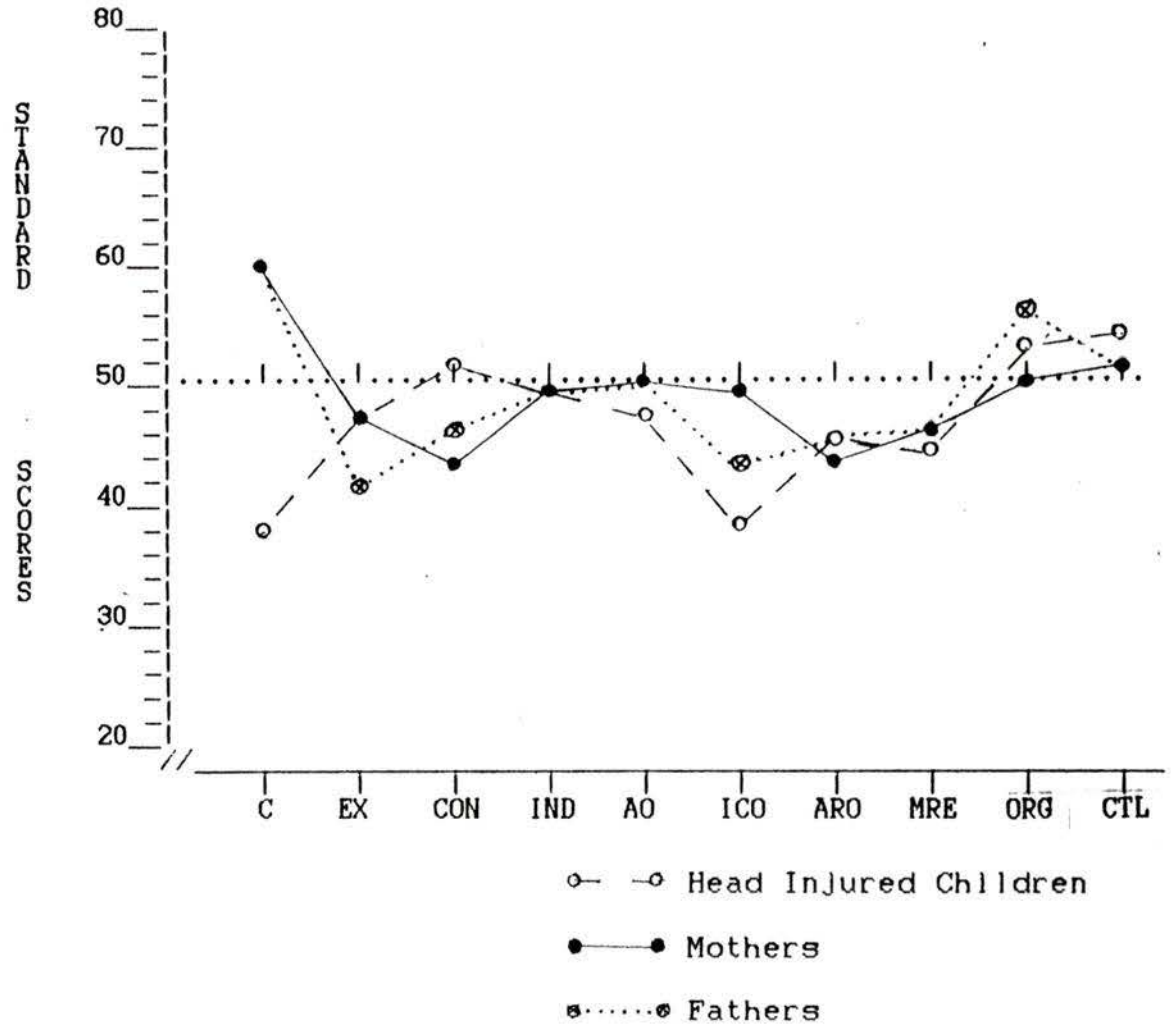
Head Injured Husbands

Wives

C - Cohesion
EX - Expressiveness
CON - Conflict
IND - Independence
AO - Achievement Orientation
ICO - Intellectual-Cultural Orientation
ARO - Active Recreational Orientation
MRE - Moral Religious Emphasis
ORG - Organization
CTL - Control

Figure 6

FES Standard Score Profiles of Severely Head Injured Adult Children and Their Parents



C - Cohesion
EX - Expressiveness
CON - Conflict
IND - Independence
AO - Achievement Orientation
ICO - Intellectual-Cultural Orientation
ARO - Active Recreational Orientation
MRE - Moral Religious Emphasis
ORG - Organization
CTL - Control

Table 13

Family Incongruence Scores for Group 1 and Group 2

	Group 1 (HIHb)	Group 2 (HICh)
Raw Score	18.875	17.705
Standard Score	57	55

(HIHb = families of severely head injured husbands)
(HICh = families of severely head injured children)

Table 14

Correlations Between Patients' and Relatives'

Perceptions of Family Environment

		Relatives	
	Wives	Mothers	Fathers
HIHb	.426	-	-
Patients			
HICh	-	.596	.721

(HIHb = severely head injured husbands)
(HICh = severely head injured children)

Discussion

Discussion of the results of this study is presented in two sections. The first section deals with the results for the total sample. In the second section, the results concerning the comparison of the two groups comprising families of severely head injured husbands and families of severely head injured adult children are discussed.

Total Sample

Descriptive data.

A brief summary of the patients' characteristics is presented in order to provide a context in which to view these patients' postinjury family environment.

Consistant with the epidemiologic literature, the majority of the patients in the present study were young (65%; 16-25yrs) males (90%). Eight of the subjects were students and the remaining 12 were employed at the time of injury. As is the case with other head injury samples cited in the literature, the major cause of injury in the present sample was motor vehicle accidents (75%).

Since the effects of head injury can vary from the trivial to the fatal, the severity of the initial injury has to be considered in any discussion of the effects on the victim's way of life. In the present study, severity of injury was defined by the length of PTA. The sample comprised of severe head injury victims only (PTA>7 days) with 80% having PTA>14 days. These patients are representative of the severe-very severe range of the severity-of-injury spectrum.

Another important factor is time elapsed since injury (Brooks, Deelman, van Zomeren, van Dongen, van Harskamp, & Aughton, 1984; Bond, 1983). There are clear differences between patients interviewed within a few months of injury and those seen several years afterwards (Brooks & Aughton, 1979; Najenson et al., 1978; Bond, 1984; Brooks et al., 1984; Livingston et al., 1985a & b). It is generally assumed that recovery is at a maximum early after injury, reducing thereafter, until by 1-2 years after injury, recovery has slowed or apparently stopped. With very severe cases, gradual functional improvement may continue beyond this point, but it is unlikely that any major changes will occur (Brown, 1975; van Zomeren & Deelman, 1978; Thomsen, 1984). More than 2.5 years had elapsed

since the time of injury for all the patients in the present sample. Ten of the subjects were between 2.5 and 5 years post injury and the remaining ten between 5 and 10 years postinjury.

Review of the postinjury employment data indicates that 60% of the sample had not returned to work or school. Two patients had resumed full-time employment, two were working in part-time jobs and 4 had returned to school. These results are similar to those reported by Oddy (1984). With a comparable group of 44 severely injured patients he reports that 57% had not returned to work 2 years after injury.

All of the patients had returned to and continued to live in the family environment after injury. Eight of the patients were husbands living with their wives, eight were adult children living with both parents, and four were adult children living with a single parent. Disability ratings indicate that all of the patients continued to show some form of disability on the DRS, ranging from mild to moderate impairment. All of the subjects were independently mobile at the time of assessment.

Depression.

The incidence of depression in severely head injured patients and their adult relatives continues to be high several years after injury. Studies of severely head injured patients indicate that between 50% - 65% of patients reveal significant psychological disturbance marked by depression and anxiety (Levin et al., 1979; Mikula & Rudin, 1983; Tyerman & Humphrey, 1984). The present study is no exception. Fifty-five percent were classified as showing significant symptoms of depression indicating that depression is a feature of the long-term outcome of severe head injury.

Thirty-nine percent of the relatives had levels of depression likely to be of clinical significance. This is more than twice the incidence of emotional dysfunction found in the general population (Finlay-Jones & Burvill, 1977). This finding is consistant with current figures concerning the incidence of emotional dysfunction in relatives 1 year after injury (Oddy, Humphrey, & Uttley, 1978; Livingston et al., 1985a & b). Unlike most emotional disorder in the general community, relatives of severely head injured patients show persistant

malfunctioning, suggesting that the underlying cause of their distress is continuing.

Subjective symptoms.

Current literature suggests that the most important predictor of relatives' psychological and social function is the level of symptomatic complaints reported by patients (McKinlay et al., 1981; Livingston et al., 1985a & b). Furthermore, several studies report that emotional, behavioural, and neuropsychological disturbances result in much heavier burden for relatives than physical disability, especially as these tend to persist longer (Panting & Merry, 1972; Thomsen, 1974; McKinlay et al., 1981; Brooks & McKinlay, 1983).

The results of the present study show that relatives continue to perceive cognitive, emotional, and behavioural changes in severely head injured patients, several years after injury. Patients also continue to make these complaints, but generally with less frequency than relatives. Of the 10 most frequently reported complaints by patients and relatives, only one, motor incoordination, referred to physical disability. The symptom triad most frequently reported by patients and relatives comprised impaired

memory and concentration, and increased fatiguability. That these deficits are particularly prevalent and persistant in severely head injured patients is generally recognized. The remaining complaints made by patients and relatives concerned emotional and behavioural changes and difficulty maintaining long-term relationships. Thus, the symptoms that have been associated with high burden in relatives of head injured patients were reported with high frequency in the present study.

The issue of systematic differences between relatives' and patients' accounts of symptoms was investigated by means of cross tabulations on patient and relative data. On questions about memory and concentration, McKinlay and Brooks (1984) report intermediate agreement (65% and 63%) between patients' and relatives' reports, 1 year after injury. In the present study, agreement between patients' and relatives' reports, 2.5-10 years after injury, is higher (memory:90%; concentration:70%). Similarly, percentage agreement of 65% on emotional and 75% on behavioural change in the present sample is higher than the 50% - 60% reported by McKinlay and Brooks. The least amount of agreement was found on questions

concerning ability to make and maintain social relationships (20% and 60%). This area was not investigated by McKinlay and Brooks (1984). These data suggest that agreement between patients and relatives concerning persistant cognitive, emotional, and behavioural problems may increase with time elapsed since injury. The patient appears to becoming more aware of his own deficits, although he is less likely to report changes in social relationships, which relatives perceive as frequently occurring problems.

Family environment.

This study addressed several issues about the perceived family environments of severely head injured patients. The first issue was whether the perceptions were systematically different from those of a normative sample. On the whole, the FES scores for the total sample of families of severely head injured patients were less than 1 SD away from the normative sample mean. These families are not showing severely disrupted environments but trends towards increased control and decreased expressiveness and recreational orientation are evident.

As predicted, the family environments of severely head injured patients were characterized by significantly higher levels of control than normal families. This finding indicates that set rules and procedures are used to run family life to a greater extent in families of severely head injured patients than they are in normal families. Furthermore, these families are less likely to make spontaneous decisions or change daily routines within the family. Set rules and procedures are of obvious value to these families when the problems reported frequently by both patients and relatives are considered. The patient with impaired memory and concentration, emotional and behavioural problems (e.g. increased loss of temper, impatience, irritability, etc.) can adapt more successfully to a rigid, stable environment and, consequently, is likely to exhibit fewer emotional/behavioural outbursts in a well controlled family setting. It is probable, that, with increasing time from injury, the family have adjusted to, or met the needs of, their severely head injured relative by incorporating defined rules and procedures within the family environment.

Families of severely head injured patients showed less emphasis on the expressiveness and

active-recreational scales than reported by families in the normative sample. Expressiveness is one of the three scales of the FES which measure the relationship dimension. The perceptions of families of severely head injured patients indicate that they do not act as openly, or express their feelings as directly, as do normal families. In this type of family environment, family members tend to communicate less about their concerns and problems and do not feel encouraged to show their emotions.

The literature suggests that there is increased friction in families of severely head injured patients, which becomes apparent 12 months after injury (Thomsen, 1974; Bond, 1984; Livingston et al., 1985b). In response to increased friction and strained relationships, it is possible that family members are suppressing overt expression of their emotions in the family setting. Again, this response may have developed with increasing time after injury. On the other hand, decreased expressiveness may also be indicative of a degree of persistant denial. In this case, family members may not express their feelings because they are not able to verbalize their concerns.

The active-recreational scale provides a quantitative measure of the degree to which families participate in activities outside the home environment. Several researchers have reported that severely head injured patients and their families become socially isolated and pursue fewer leisure activities (Thomsen, 1974, 1984; Rosenbaum & Najenson, 1976; Lezak, 1978). This finding is consistant with the low emphasis on the active-recreational scale reported by families in the present sample.

The degree of overall agreement between relatives' and patients' perceptions of their family environment was high. The least amount of agreement occurred on the independence scale. Adult relatives perceive less opportunity for independent activity than do patients. This result is not surprising if, as suggested by Lezak (1978) and Blazyk (1983), relatives have assumed predominantly caretaking roles in the family environment. Having taken on more caretaking responsibilities, the relative is much less likely to perceive or, in fact, achieve the opportunity for independent activity.

The second issue addressed in the present study was whether the perceived family environments of

families of severe head injury victims were significantly different from those of other distressed families. Families of severely head injured patients report significantly more cohesion and organization than do other distressed families. Emphasis on the organization scale of the system maintenance dimension again highlights the relative importance placed upon clear organization and structure in planning activities and responsibilites in families of severely head injured patients. Furthermore, family members perceive their environment as being more supportive than is generally the case with other distressed families.

The literature suggests that families in crisis, and under continuing stress, become less cohesive, less well organized, and report more conflict (Scoresby & Christenson, 1976; Young et al., 1979). This pattern may well be associated with early family response to severe head injury. However, as time from injury increases, and if the family remains intact, the long-term outcome is characterized by increased cohesion and organization and less conflict. These features may reflect long-term adjustment to a changed situation.

Despite this apparent adjustment within the immediate family environment, social isolation associated with low emphasis on the recreational scale is a common feature among these families, several years after injury. As suggested by Lezak (1978), Thomsen (1974, 1984), and Blazyk (1983), family life may have become centred around the needs of the injured person to the point where the family unit becomes isolated in its social setting. The lack of emphasis on social and leisure activities is similar to that reported by other families with one dysfunctional member.

Group Comparisons

Two distinct groups of families were included in this study. The groups differed with respect to the role of the severely injured patient in the family. The first group comprised head injured husbands and their wives and the second, head injured adult children and their parents. Group comparisons were conducted on all the measures employed in the study in order to ascertain potential differences between these two groups.

Descriptive data.

A review of the descriptive data for the two groups indicates that they are similar in many respects. There were eight families in both groups and the patients were all males. PTA was greater than 14 days for all the patients and the mean disability rating was in the partial disabilty range for both groups. The mean family size in both groups was 3.50. The major differences between the two groups involved age at time of injury and time elapsed since injury.

Depression.

The incidence of depression in both patients and relatives in the two groups differed markedly. Of the eight severely injured husbands, seven were classified as depressed. In contrast, only two of the eight severely injured adult children showed levels of depression likely to be of clinical significance. A similar picture was found with the relatives in the two groups. Seven of the wives and only one set of parents were classified as depressed.

With such small numbers it is difficult to draw firm conclusions from this data. Previous research has not looked at incidence of depression in severely head

injured patients according to their role in the family setting. It is possible that the psychological and social consequences of severe head injury are more disruptive and distressing for adults who have moved away from their original family environment, married, and set up their own homes. Thus, as a result of the role changes experienced by severely head injured husbands, they may be more vulnerable to chronic depression than severely head injured adult children.

Two divergent views have been reported in the literature concerning psychological dysfunction in relatives of severely head injured patients. Panting and Merry (1972) and Thomsen (1974) suggest that mothers are better able to cope with the burden of living with a severely head injured relative than are wives. Livingston et al. (1985a,b) report a similar pattern of psychological and social dysfunction in wives and mothers of severely injured patients. Both Panting and Merry's and Thomsen's study involved patients and their relatives more than 2 years postinjury. In the Livingston study, families were interviewed 12 months after injury. It is possible that a different pattern of psychological dysfunction emerges in wives and mothers as time from injury

increases. Bearing in mind the small size of the present sample, the results indicate that wives do appear to be more likely to experience depression than mothers (or fathers) of severely head injured males. There are several possible reasons for this difference. Firstly, all the adult children were living with both parents and, consequently, two people could share the burden imposed by the injured person. In contrast, the wives did not have another adult in the family setting with whom to share the burden. Secondly, the role changes in marriage imposed by a severe head injury are greater than those that occur in families of severely injured adult children. Thirdly, parents may be more able to tolerate or adjust to the behavioural changes that occur as a result of severe head injury.

Subjective symptoms.

All the severely head injured adult children reported fewer symptoms than did their parents. They also reported fewer symptoms than the head injured husbands in the sample. There was little difference between the complaints mentioned by head injured husbands and their wives. Reports of relatives in both groups (wives and parents) were similar with respect to

the number and nature of the symptoms perceived in the head injured family member. Thus, both groups of relatives appear to be dealing with similar changes in their head injured family member.

The fewer number of symptoms reported by the severely injured adult children may be related to time elapsed since injury. The mean time elapsed since injury for this group was 3.75 years, while an average of 6.37 years had elapsed for the severely head injured husbands group. As suggested earlier in the discussion, it is possible that head injured patients' accounts of perceived changes more closely match the accounts of relatives as time from injury increases. That is, severely head injured patients develop increasing insight and tend to deny their own deficits and emotional and behavioural changes less, as time from injury increases. This process may continue for several years and beyond the time that recovery of cognitive processes is thought to have stopped. It is possible that the low incidence of depression in the head injured children is related to the number of symptoms that they report. There may be a concomitant increase of depression with increasing awareness of deficits as time from injury increases. Longitudinal studies of

severely head injured patients and their relatives beyond 1-2 years post injury will permit better understanding of this phenomenon.

Family environment.

The final issue that was addressed in the present study was whether systematic differences in perceptions of family environment existed between families of severely head injured husbands and families of severely head injured adult children, 2-10 years after injury.

As predicted, the families of severely head injured husbands reported significantly less cohesion and more conflict than families of severely head injured adult children. They were also much less likely to participate in activities outside the immediate family environment and thus, appear to be more socially isolated than families where the head injured member is an adult child. Overall, scores on the three scales of the relationship dimensions indicate that the family environment of severely head injured husbands is characterized by markedly more friction than is evident in families of severely head injured adult children.

Families of severely injured husbands do not appear to be functioning well. Their perceptions of the

family environment are consistant with a high level of continuing distress, which in some cases had reached crisis point. In contrast, families of severely head injured adult children are doing well. There is little apparent friction in family relationships and these families are less isolated in their social environment. These results suggest that severe head injury may be associated with different outcome for the family unit dependent upon the role of the injured family member.

Unfortunately, there are no studies with which to compare the family environment data. However, there are studies which have reported relevant findings concerning family relationships and social adjustment after severe head injury. Many of these studies did not specifically consider the possible effect that the patient's role in the family might have on overall outcome. That is, where relatives were interviewed it is not clear whether they were spouses or parents of the head injured subjects (Bond & Brooks, 1976; Lezak, 1978; Oddy & Humphrey, 1980; McKinlay et al., 1981).

It is suggested that findings about the increased vulnerablity of marital relationships to the consequences of severe head injury (Panting & Merry, 1972; Thomsen, 1974; Livingston et al., 1985b) can be

extended to other aspects of the family environment and the family unit as a whole. The reasons for this are likely to be similar to those discussed with respect to the higher incidence of depression found in wives, as compared to parents, in the present study. That is, wives do not have another adult in the family unit with whom to share the burden of the consequences of the head injury. In many cases the responsibilities that were shared between husband and wife before the injury are assumed entirely by the wife after the injury (Rosenbaum & Najenson, 1976). In the present study wives perceive very little opportunity for independent activity within the family setting. Increased caretaking responsibilites generally lead to decreased independence. The role changes imposed by severe head injury in families of severely head injured husbands are greater than those which occur in families of severely head injured adult children. Finally, it may be the case that parents are better able to tolerate the changes that occur as a result of the injury.

In the sample of families studied, it is noteworthy that seven of the eight head injured husbands and their wives were classified as depressed. Only one set of parents and two head injured children

in the second group showed levels of depression likely to be of clinical significance. It is possible that the persistant emotional dysfunction in wives and husbands affects their perceptions of the family environment. Bromet, Ed, and May (1984) used the FES to study the family environments of depressed outpatients. They found no statistical difference between the family environments of depressed patients and families in a normative sample. They conclude that high levels of marital conflict in their sample could not be extrapolated to the family as a whole. Thus, there is some evidence to suggest that the disturbed family environments of the severely head injured husbands in the present study are not a simple reflection of the depression noted in the subjects at the time of assessment.

The mean time elapsed since injury for families of severely head injured husbands was almost twice that of families of severely head injured adult children. This difference raises the possibilty that family outcome may in fact deteriorate as time from injury increases. Brooks and McKinlay (1983) suggested that relatives' ability to tolerate the emotional and behavioural changes that result from severe head injury decreases

over time. Their study spanned the 2 years following injury and it is not known whether this process continues beyond this point. The experimental design and the nature of the sample, in the present study does not permit clarification of this issue. Longitudinal studies of larger groups of families are warranted.

SUMMARY

This study has attempted to evaluate the family environments of patients who sustained a severe closed head injury 2-10 years previous to the time of testing. The following is a summary of the major findings.

1. Severely head injured patients and their close, adult relatives continue to show a high incidence of depression, several years after injury. Severely injured husbands and their wives appear to be more vulnerable to depression than severely injured adult children and their parents.

2. Cognitive, emotional, and behavioural symptoms continue to be the most frequently reported complaints of patients and relatives. Agreement between patients' and relatives' accounts of persistant symptoms may increase as a function of time elapsed since injury.

3. There is evidence that the family environments of severely head injured patients differ significantly from those of a normative sample. The family environments of severely injured patients are characterized by more control i.e. set rules and

procedures. These families are less expressive and less oriented to recreational pursuits than normal families.

4. Several years after injury, families of severely head injured patients differ significantly from other distressed families. Family members perceive their environment as being more cohesive and more well organized than other families with one dysfunctional member.

5. The role of the severely injured patient in the family unit appears to affect the long-term outcome for these families. The family environments of severely head injured husbands are characterized by more conflict, less cohesion, and less emphasis on social and leisure activities than those of severely head injured adult children. Families of severely head injured adult children appear to function more effectively than families of severely head injured husbands.

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APPENDIX A

DESCRIPTIVE DATA

Table A-1

Frequency Analysis of Age at Time of Injury

(n = 20)

Age (yrs.)	Absolute Frequency	Relative Frequency (%)
16 - 20	10	50
21 - 25	3	15
26 - 30	2	10
31 - 35	1	5
36 - 40	4	20

Table A-2

Frequency Analysis of Preinjury Marital Status

(n = 20)

Marital Status	Absolute Frequency	Relative Frequency (%)
Single	11	55
Married	9	45

Table A-3

Frequency Analysis of Level of Education Completed at Time of Injury

(n = 20)

Grade	Absolute Frequency	Relative Frequency (%)
9	4	20
10	3	15
11	0	0
12	11	55
Coll/Univ	2	10

Table A-4

Frequency Analysis of Preinjury Employment

(n = 20)

Employment	Absolute Frequency	Relative Frequency (%)
Full time	12	60
Unemployed	0	0
Student	8	40

APPENDIX B

INJURY RELATED DATA

Table B-1

Frequency Analysis of Cause of Injury

(n = 20)

Cause	Absolute Frequency	Relative Frequency (%)
Moving Vehicle Related	15	75
Auto - Passenger	7	35
Auto - Driver	4	20
Motorcycle - Passenger	1	5
Motorcycle - Driver	1	5
Pedestrian	2	10
Non Moving Vehicle Related	5	25
Accident at Work	4	20
Assault	1	5

Table B-2

Frequency Analysis of Length of Hospitalization - Acute Care

(n = 20)

Duration	Absolute Frequency	Relative Frequency (%)
7 - 28 days	11	55
1 - 3 months	7	35
> 3 months	2	10

Table B-3

Frequency Analysis of Length of Posttraumatic Amnesia (PTA)

(n = 20)

PTA	Absolute Frequency	Relative Frequency (%)
8 - 14 days	2	10
15 - 28 days	7	35
1 - 2 months	7	35
> 2 months	4	20

APPENDIX C

INTERVIEW DATA

Table C-1

Frequency Analysis of Time Elapsed Since Injury

(n = 20)

Injury - Assessment Interval (yrs)	Absolute Frequency	Relative Frequency (%)
2 - 4	10	50
5 - 7	7	35
8 - 10	3	15

Table C-2

Frequency Analysis of Age at Time of Interview

(n = 20)

Age (yrs)	Absolute Frequency	Relative Frequency (%)
18 - 20	4	20
21 - 30	9	45
31 - 40	3	15
41 - 45	4	20

Table C-3

Postinjury Living Circumstances

(n = 20)

Head injured Subject	Adult Relatives	No. of Families	Mean Size of Family
Child	Parents	8	3.50
Child	Sgl Parent	4	2.25
Husband	Wife	8	3.50

Table C-4

Frequency Analysis of Employment Status at Time of Interview

(n = 20)

Employment	Absolute Frequency	Relative Frequency (%)
Full time	2	10
Part time	2	10
Unemployed	12	60
Student	4	20

Table C-5

Frequency Analysis of Presence/Absence of Litigation/Compensation

(n = 20)

Litigation/Compensation	Absolute Frequency	Relative Frequency (%)
None	0	0
In progress	6	30
Completed	14	70

Table C-6

Frequency Analysis of Seizure History

(n = 20)

Seizures	Absolute Frequency	Relative Frequency (%)
None	11	55
Past	7	35
Present	2	10

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Title of Thesis

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Author [redacted]

MARY JACINTA DOUGLAS

April 24th, 1987