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THE PSYCHOSOCIAL CONSEQUENCES OF SEVERE HEAD INJURY
FROM THE PERSPECTIVE OF RELATIVES WHO CARE FOR
HEAD-INJURED PERSONS IN THE COMMUNITY;
A CROSS-SECTIONAL CASE STUDY APPROACH

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ABSTRACT

The primary aim of this research was to gain insight into the "world" of carers of head-injured persons in the community, identify their major areas of stress, and explore support needs. A cross-sectional multiple case study design was chosen. The patient sample had all experienced severe to extremely severe head injuries. They were not interviewed. Semi-structured interviews were conducted with eleven carers of the head-injured persons, all but one being a relative of the patient. A verbally-administered questionnaire was used during the interviews to ensure that standardised questions were asked of all respondents. Many of the questionnaire items were closed, but others were partially or fully open-ended. The questions addressed: historical information, changes in the patient, changes in overall life-style, changes in relationships, carers' personal and practical support needs, and their perceptions of the future. A single quantitative analogue rating scale was used to measure levels of respondents' reported distress. Respondents were encouraged to provide comments freely during the interviews. The obtained data was systematically presented in the form of group frequencies and occasional measures of central tendency. This data was supplemented by eleven individual case studies. The main patterns and themes were apparent in the grouped data, but the individual case studies permitted examination of both common and unique responses within a "real life" context. There was thus across-study and within-study investigation. The approach to the research was exploratory and descriptive. No hypotheses were held but some expectations were indicated in the existing literature. The present study found similarities with previous research in that psychosocial changes in the patient were reported more frequently by carers than broadly physical changes, reported stress levels were generally high, and there were complaints by respondents about lack of head injury information, and lack of family counselling. The most notable differences were that respondents in this study considered that

(in terms of reported frequencies) communication, conversation and interactional changes in the patients, together with patients' social restrictions/isolation, were the most distressing changes for the carers. A major area of reported distress by respondents in this study related to insensitivity by others towards the patient. However, a number of positive, optimistic comments were made by respondents. Practical support needs were generally met, as were personal support needs in the form of confidantes and friends. The methodological limitations of the present study were discussed, and theoretical and practical implications examined. Suggestions were made for further research.

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CHAPTER 1

INTRODUCTION

Carers of head-injured persons in the community deserve special recognition. Their role is one which has usually been thrust upon them, and for which they receive little or no training. Living with, and caring for, a severely head-injured family member can result in major disruptions to a previous life style and a high level of experienced stress.

The primary aim of the present study is to gain insight into the "world" of those caring for head-injured persons in the community, and to identify and explore both the carers' major areas of stress and their support needs. There are two secondary aims: the first of these is to examine the findings in the context of previous relevant research, and the second is to provide information which may be of assistance to agencies and professionals involved in rehabilitation fields.

There have been a great number of studies into the effects of head injury in terms of resultant patient deficits, especially those of neurological origin. In contrast, research into the psychosocial effects of head injury within the context of the family has received relatively much less attention. Although interest has been growing during the past decade, there is still a need for a great deal more research. This is indicated by the present relative absence of comprehensive models and unified theories.

The research carried out to date indicates that relatives of head-injured persons experience high levels of stress (Brooks et al, 1986; Livingston et al, 1985; Oddy et al, 1978a; Panting & Merry, 1972; Rosenbaum & Najenson, 1976). There is substantial evidence from these studies that the emotional and behavioural changes in the head-injured family member contribute in a major

way to the carer's stress. However, the multi-dimensional nature and effects of other variables on a carer's stress have been less well researched (e.g. changes in roles and relationships, changes in life style, non-provision of personal and practical support, and so on). Identification and description of these variables is seen as a necessary prerequisite to the formulation of hypotheses; in turn, these hypotheses form a basis for systematic applied research. Only minimal research has been carried out in New Zealand and this has focused on patients, although family difficulties have been noted (Blyth, 1981; Crawford, 1983).

It is not the intention of the present research, then, to test hypotheses but, rather, to collect data which will allow hypotheses to be generated. In presenting eleven individual case studies, supplemented by standardised data from a questionnaire administered to all respondents, it is seen that the descriptive data subsequently presented will have a depth and breadth often lacking in conventional quantitative designs. The present essentially qualitative approach permits the examination of both common group patterns, and individual or unique experiences. It does not subsume individual differences in group data. Identified group patterns, however, provide information which can be valuable in formulating rehabilitation policy with a holistic, family-oriented focus.

The present study's design is not a new or novel approach in the area of relevant research. Instead, it seeks to make a contribution which will enlarge existing findings. Similarities and differences in the present study's findings, relative to previous research, will serve to provide additional data in consideration of issues of overall validity and reliability in the general area of the research. The questionnaire used in the present research is derived from that used in earlier studies in Glasgow (Brooks & Aughton, 1979).

The present thesis contains eight chapters. Following on from this first chapter, chapter 2 will examine the literature as it relates to head injury per se. Chapter 3 continues the literature review by examining the family in relation to head injury; these two chapters are inter-related but each contains a change of focus, and together they provide an overall context within which the present study can be viewed. Chapter 4 discusses the aims and design of the present research. Chapter 5 describes the sample, and the material and procedures used in this study, while chapter 6 presents the results in two sections. Chapter 7 discusses the results of the present study. Chapter 8 summarises the findings, discusses the methodological limitations of the present study, examines its theoretical and practical implications, and makes suggestions for further research.

CHAPTER 2

HEAD INJURY

This chapter examines the physical, psychological and social consequences of head injury by reviewing the relevant literature. Definitions of head injury and its epidemiology are also discussed. The purpose is to provide a context within which the present research can be viewed. The next chapter will examine literature relative to the family and carers of head-injured persons.

Definitions

Two major types of head injury are recognised. Open (or penetrating) head injury is caused by an object fracturing the skull, entering the brain, and damaging brain tissue in its path. The penetration carries a risk of introduced infection, but brain lesions are relatively localised. In contrast, closed (or blunt) head injury is the result of a blow to the head which causes damage to, and stretching and twisting of, brain tissue as the brain impacts against the skull (Corthell & Tooman, 1985; Vogenthaler, 1987a). Closed head injuries are relatively much more common than open head injuries, except in times of war. Injury to the head as a result of an accident is also referred to as traumatic brain injury or craniocerebral trauma, in order to distinguish it from cerebrovascular incidents such as strokes.

There is a further categorisation of head injuries into minor and severe types. A "minor" head injury involves no loss, or only a brief loss, of consciousness; there is no clinical or radiological evidence of fracture or brain damage, and there is relatively rapid return to normal function. The minor head injury is almost exclusively a closed injury. The second category, "severe" head injury, involves prolonged and deep loss of consciousness (coma), followed by post-coma confusion and some degree of post-traumatic amnesia. This type of head injury can

be either closed or open (Allen, 1986; Ellis & Zahn, 1985; Lishman, 1973).

Epidemiology

Incidence. Closed head injury has been described as a "silent epidemic" (National Head Injury Foundation, 1979). Studies in the United States have reported an incidence of 422,000 cases of traumatic head injury per year: that is, approximately one person in every 500 of the population. These numbers exceed the annual incidence of all other neurological impairments combined, with the exception of stroke (Dixon et al, 1988). While the majority of these injuries are classified as mild, some ten per cent of the annual survivors are left with moderate and severe head injuries (Vogenthaler, 1987a). The incidence of registered head injuries in Sweden is 3.0 to 3.6 per 1000 of the population (Hook, 1988).

As is the case in other countries (Badcock, 1988; Field, 1976), statistical data for New Zealand are difficult to obtain. The Department of Health details the annual number of patients discharged from public hospitals where the main reason for admission has been "fracture of skull" or "intracranial injury". These numbers include re-admissions. In cases of multiple severe injury, head injury may not have been recorded as the primary diagnosis. Estimates, however, are that some 6000 head injured patients are discharged from public hospitals each year (New Zealand Department of Health, 1985). This represents approximately one person in every 500 of the population. Cases of non-hospital admission and cases of fatalities are obviously not included in these figures. Wrightson & Gronwall (1982) estimate that hospital admissions account for only half of the mild head injuries in New Zealand, and that mild head injuries represent more than one-half of all head injury cases admitted to New Zealand hospitals. The annual incidence of head injuries in this country, then could be as high as 10,000, or approximately one person in every 300 of the population.

For the year ended March 1989, the Accident Compensation Corporation (New Zealand) registered 5093 claims with a diagnosis of "injury to the head" (excluding face). There were 4105 males and 988 females. Additionally, the statistics show that a relatively large number of claims were categorised as "multiple locations" (7254) which may also include head injuries (Accident Compensation Corporation, 1989). The limitations of the Corporation's statistics are that they tend to exclude: (a) injuries to non-earners, unless compensation other than an earnings-related benefit was paid; (b) short-term incapacity (one week or less off work); and, cases requiring only GP or para-medical treatment, and where the costs of this treatment were charged direct to the Corporation (no formal claim lodged by the patient). Mild head injuries, and injuries to housewives and the elderly, then, are likely to be under-represented in these statistics. An under-representation of housewives and elderly women may account, in part, for the relatively very high ratio of male to female injuries (4:1) relative to reported incidence in other countries. The Department of Health statistics indicate a lower ratio of males to females (slightly more than 3:1).

Causes. Accidents involving motor vehicles account for approximately half of all head injuries. Research has shown this to be consistent across a number of countries. Additionally, the more severe the injury, the greater the likelihood that it was caused by a motor vehicle accident. Other causes include falls, assaults, occupational injuries, and sports injuries (Allen, 1986; Rimel & Jane, 1983).

Demographic characteristics. In the United States, males are two or three times more likely to be injured than females. The brain injured population there is predominantly young: seventy per cent of head injured people are under 30, and the majority of this group are aged 15 to 24. Lower socio-economic groups tend to be over-represented in the head injured population, as do alcohol and drug abusers. Those who have

already experienced previous head injury are at greatly increased risk of further head injury (Gale et al, 1983; Rimel & Jane, 1983; Vogenthaler, 1987a). Similar patterns are apparent in Britain, although Bond (1984) reports that there is a second peak of head injury incidence at over age 70.

Measurement of severity

The severity of the injury itself is usually measured by length of post-traumatic amnesia (PTA) or duration of coma.

The PTA classification is based on: very mild (over 5 minutes), mild (over 1 hour), moderate (1-24 hours), severe (1-7 days), very severe (over 7 days), and extremely severe (over 4 weeks). The advantage of the scale is that PTA can be used to measure the severity of injury without requiring early medical records or witnesses. The end of PTA often correlates with the end of the patient's confusion (Yarkony et al, 1983).

The Glasgow Coma Scale assesses the depth and duration of coma. Three aspects of behaviour are measured independently: motor responsiveness, verbal performance, and eye opening. This scale provides a definition of coma and allows for comparisons among patients. It is easily recorded and understood by different staff (Jennett & Bond, 1975; Yarkony et al, 1983).

The Glasgow Outcome Scale assesses overall disability - that is, the net effect of the injury on the functioning of the individual or overall social outcome of head injury (Jennett & Bond, 1975; Jennett et al, 1981). The Glasgow Outcome Scale has five overall outcome categories: death, persistent vegetative state, severe disability, moderate disability, good recovery. The advantages of the scale are that it is relatively fast and unobtrusive, and it has been used worldwide, allowing for comparison of head injured groups in different countries. The limitations of the scale are that it is a gross or overall measure and does not assess individual problems in long-term

social rehabilitation (Elsass & Kinsella, 1987). The age of the patient at injury also affects outcome: with increasing age, there is less difference in outcome between mild and severe injuries (Jennett & Bond, 1975).

Research has shown that behavioural disturbance (cognitive, motor, emotional and affective) is positively related to severity of the initial injury (Levin & Grossman, 1978). However, Brooks (1988) comments that, although the more severe the injury, the greater the likelihood of any deficit, there are predictive difficulties. The first involves the definition of the severity of underlying brain damage, and the second involves extrapolation from group studies to an individual patient. Additionally, the diffuse lesions resulting from closed head injury are frequently compounded by focal lesions such as haematomas.

Stages of recovery

As the result of ten years' research into the physical and psychological consequences of severe head injury, Bond (1979) has described the process of recovery in terms of identifiable stages. At first, the patient is unconscious as the brain reacts physically to diffuse brain damage; this stage extends from a few days to several weeks. In the second stage, he or she regains consciousness, and displays evidence of relatively rapid improvement in basic physical and mental functions; this stage is also characterised by the end of post-traumatic amnesia. The rate of recovery then slows (usually within six months of the injury) and the third stage of adaption to the residual disabilities begins; this stage may last for many months. Further recovery may occur but the rate and extent is reduced by comparison with the second stage. The disability can thus be considered relatively "fixed" by six months or by the time the third stage is reached (Bond & Brooks, 1976; Groswasser et al, 1977; Yarkony et al, 1983). The age of the patient needs to be considered, however, as younger brains are more "plastic" and there is better prognosis for recovery.

Deficits following severe head injury

These deficits are varied and they relate to the physical, cognitive and psychosocial functions mediated by the brain. While the physical changes are usually obvious, and sometimes serious, there is general agreement that the behavioural changes, although more subtle and difficult to recognise, have a more profound effect on the life of the patient and those with whom he or she associates (Ben-Yishay & Diller, 1983; Brooks, 1988; Lezak, 1978a; Oddy et al, 1978b; Rosenbaum & Najenson, 1976). Deficits result from both diffuse damage to the brain and from injury to localised areas. Specific deficits are often attributable to damage to specific areas of the brain and its functions. Cognitive, motor, emotional and affective disturbance is positively related to severity of initial injury (Levin & Grossman, 1978).

Physical and neurophysical impairment

Motor deficits are common and include: tetraplegia, paraplegia, hemiplegia and hemiparesis; ataxia; reduction of fine and gross motor dexterity; balance difficulties; and loss of endurance. The production of speech may be difficult, two examples being those of dysarthria and apraxia. Sensory function relating to visual and auditory perception, and tactile sensation may be impaired. Early or late onset of epilepsy is not uncommon: post-traumatic epilepsy develops in five per cent of closed head injuries and thirty to forty-five per cent of open head injuries. (Corthall & Tooman, 1985; Newman, 1984; Vogenthaler, 1987a). It is to be remembered that many patients suffer multiple injuries in accidents, of which the head injury may be only one feature. Orthopaedic injuries and joint contractures may add to the patient's physical difficulties (Najenson et al, 1974).

Cognitive impairment

The cognitive disturbances are well recognised. These include: deficits in learning, memory, attention, arousal, concentration,

concept formation, problem solving, perception, and language skills (Brooks, 1988; Vogenthaler, 1987a).

(a) Memory and learning. There may be difficulty with both retrograde amnesia (pre-injury events) and short term memory loss (post-injury events), although short-term memory deficits are more usual. Long term memory loss involves difficulty with remembering distant events, or transmitting recent events into long-term storage. In very severe cases, the head-injured person may be virtually unable to learn new information due to problems with memory recall. The memory deficits are very pervasive and evidenced in a wide variety of test procedures. They relate to both verbal and non-verbal tasks. The problems may be attributable to diffuse brain damage, although persons with left hemisphere mass lesions have a particular propensity to learning or language deficits. Individuals with large bifrontal lesions tend to "fail on memory tasks because they approach the task in a chaotic, unstructured and ineffective manner" (Brooks, 1988, p.41).

(b) Attention and concentration. Deficits in attention and concentration produce an inability to filter out irrelevant background stimuli and the head-injured person is easily distractable. This tends to be particularly apparent during unstructured or extended tasks. Studies of reaction time suggest that there is a slowing of information processing.

(c) Arousal. The head-injured person may have difficulty in maintaining any consistent degree of alertness and remain lethargic. He or she may give the impression of being drowsy, retarded in thought, and passive in the face of changing stimuli. Arousal disorders can be associated with motivational disorders in that a patient describes an interest but fails to show any such interest.

(d) Concept formation and problem solving. The head-injured person may focus on only the concrete aspects of situations or

conversations. There is difficulty in generalising learned solutions to new problems; similarly, there may be inability to generate different solutions for a given problem, and a tendency to persevere with an inappropriate solution.

(e) Perception. Perceptual deficits encompass visual-motor co-ordination and spatial relationships; they are linked to inattention and neglect in that the person does not attend to one side of the visual field, or neglects one side of the body.

(f) Language. Aphasia is a language deficit and takes two common forms: the expressive type (difficulty in expressing verbal and/or written thoughts); and, the receptive type (inability to comprehend written and/or oral language, perhaps including one's own speech). Other language disorders include dysnomia, dyslexia, and dysgraphia (Corthell & Tooman, 1985; Kay & Silver, 1988; Vogenthaler, 1987a; Wood, 1984).

"Executive" deficits

Patients with bilateral frontal damage frequently suffer from "executive deficits". Sometimes described as "impulsivity" or "thinking disturbance", these deficits take the form of an inability to be self-directing and self-initiating; there is difficulty in executing plans. In cognitive tasks, the head-injured person fails to carry out a rational and appropriate analysis of the requirements of the task and makes inappropriate, apparently impulsive errors. There is a tendency to establish unrealistic goals and a failure to learn from mistakes. Inappropriate social behaviours are not recognised and changed. The head-injured person appears to be oblivious to the "executive" deficits and frequently fails in vocational settings, despite technical competence (Brooks, 1988; Vogenthaler, 1987a).

Psychosocial deficits

Soon after the injury, the head-injured person may display

agitation, violence, delirium, hallucinations, and unpredictable behaviours. These are associated with reduced consciousness level and almost always diminish over time. The behaviours that tend to persist include: irritability, impatience, impulsivity, poor frustration tolerance, denial, anxiety, depression, anger and childlike dependency. Some pre-morbid personality traits, especially those that are least attractive, may become exaggerated. However, some five per cent of head-injured persons become more placid and pleasant after the injury (Brooks, 1988; Vogenthaler, 1987a).

A "frontal syndrome" group of emotional changes has been described, each consequent upon destruction of tissue in different areas of the frontal lobes (Bond, 1984; Brooks, 1988; Newman, 1984; Vogenthaler, 1987a). These include emotional and sexual disinhibition, altered sexual drive, emotional blunting, extreme self-concern and egocentricity, lack of tact and concern for others, and general childishness. Typically, drive levels are reduced and plans are not followed through; the effects can be profound on the person's social and vocational life. Roberts (1979), in a longitudinal study of severely head-injured persons, found that some forty per cent of his sample demonstrated some form of emotional disturbance associated with frontal lobe damage. Other described forms of emotional change include irritability, emotional lability, stubbornness, restlessness, pathological laughter and weeping, and outbursts of rage and aggression (Newman, 1984).

Newman (1984) considers that, although emotional disturbances may follow directly from cortical damage, these disturbances may also occur as a result of the person's reaction to physical and/or cognitive loss. Newman also considers that cortical damage may disrupt the individual's ability to interpret the world appropriately, leading to apparently disturbed emotional responses. Similarly, Prigatano (1987) suggests that three types of personality disorders can be conceptualised:

neuropsychologically mediated disorders; reactions to brain injury and associated failures in coping; and personality disorders that existed pre-injury which are characterological in nature.

The changes described sometimes lead to secondary changes as a result of other people's altered mode of interacting with the head-injured person (Brooks, 1988).

Rehabilitation

Rehabilitation follows the acute medical phase of treatment. Initially, this focuses on physical restoration and will ideally take place in a hospital rehabilitation unit or specialised rehabilitation hospital. The goal is to ameliorate physical deficits that interfere with daily living activities but there is an increasing attention to the cognitive, executive, and psychosocial disabilities resulting from head injury. The ideal is a multi-disciplinary team approach, with goals and targets being set for individual patients (Brooks, 1988; Vogenthaler, 1987b). There has been a very large increase in this type of programme in the United States in recent years, but in the United Kingdom rehabilitation facilities are not well developed (Livingston, 1986). This is also the case in New Zealand (Blyth, 1981; Crawford, 1983). The concept of case management practice in which the head-injured person's rehabilitation is co-ordinated by a designated person has many advantages and is becoming more widely accepted (Dixon et al, 1988).

Most survivors of head injuries are young and have full life expectancy. Rehabilitation measures that result in improvement in the final level of functioning, reduce reliance on services, and achieve some form of economic independence for the individual are seen to be of increasing importance (McKinlay & Pentland, 1987).

The rehabilitation of severely head-injured people is made particularly difficult by what Vogenthaler (1987a) describes as

"patterns of inconsistency" and an interplay between "micro and macro deficits". For example, micro-deficits such as speech difficulties may combine with decreased attention span and memory problems to form macro-deficits. A physical deficit such as hemiparesis, already affecting independent living, is compounded when accompanied by other problems such as cognitive deficits. Additionally, a head-injured person may display inconsistency in demonstration of skills: not only may an individual's performance be good on one occasion and poor on another, but there may be inconsistency both within and across skill areas.

McKinlay & Brooks (1984) have found that head-injured patients typically underestimate the severity and functional impact of their cognitive and other deficits. Prigitano (1987) considers that unawareness of deficit is one of the major predictors of outcome but there is little systematic empirical research data supporting this point of view.

Behavioural therapy is a technique now being used in the rehabilitation of the head-injured. Wood (1984) comments that behavioural problems actively interfere with the rehabilitation process and the social acceptability of the head-injured person. Wood refers to positive behaviour disorders (aggressive behaviours, sexual behaviour and attention seeking), negative behaviour disorders (arousal and motivational disorders), and dissociative disorders (hysterical states, manipulation of staff, failure to work for some reward, refusal to make any effort to avoid punishment). He considers that the methods available for behavioural learning with the head-injured are no different from those used with other groups, except in the manner of technique application. Muthny & Haag (1987), however, consider that although individual trials are promising, there has been inadequate research and evaluation of the therapeutic results.

van Zomeren et al (1984) describe the "coping hypothesis" of the head-injured: the head-injured person has a decreased rate of

information processing, often associated with memory deficits. In order to cope with daily life, he or she will try to compensate for the deficits by expending greater effort. When the compensatory effort becomes chronic, secondary symptoms may appear; these are similar to those found in people who have been subject to chronic stress for a prolonged period. This may lead to the head-injured person being classified as "neurotic".

Psychological counselling is seen as very important in assisting the head-injured person to come to terms with their present strengths and weaknesses. Additionally, it should be available to aid the individual in handling the inevitable stresses and failures that occur during the rehabilitative period (Vogenthaler, 1987b).

The pre-morbid personality of the head-injured person is a factor to be considered in rehabilitation. Brooks (1988) comments that a person who was a driving and achieving person pre-morbidly may continue to display these aspects of personality post-injury, leading to relatively positive outcomes. In contrast, a passive, under-achieving person may retain these traits after the injury. Management of the person by others, including the family, also plays an important part. Oddy & Humphrey (1980), in a study of fifty-four patients, found evidence to support the view that pre-morbid personality affects social recovery. Bond (1984) also comments on the pre-morbid personality of the head-injured individual. He has found that exaggeration of pre-morbid traits after injury is common. The effects of primary brain injury may lead to the moderation of previously objectionable behaviour, although this is one of the less common consequences of brain damage. Primary brain damage may also obliterate most of the patient's pre-traumatic personality characteristics and behaviour and replace them with organically determined features.

Lezak & O'Brien (1988) report on a longitudinal study of thirty-nine male head-injured patients which had documented their

progress during the first five years following the injuries. Many had suffered relatively mild brain injuries. It was apparent that the subjects' social competency played an important part in their quality of life and capacity for rehabilitation or employment. Over the period of the study there had been marked improvement in areas such as independent living, initiative, leisure activities and ambulation. In contrast, five years after their injuries, most subjects were still socially dysfunctional in one or more areas. Newton & Johnson (1985) have also reported on the presence of social anxiety, poor social performance, and low self-esteem in severely head-injured persons.

One of the major problems facing head injured persons over time is that of social isolation (Thomsen, 1985). Prigatano (1987) considers that if individuals can be taught to compensate for their deficits, acquire a realistic view of what they can and cannot handle, and obtain a level of employment compatible with their abilities, there is a chance of re-establishing some meaning in their life.

Najenson et al (1974) studied the results of medical rehabilitation in a sample of 169 patients. Negative prognostic factors in rehabilitation were: prolonged coma, age older than 45, severe neurological motor deficits, epilepsy, aphasia and hemi-anopsia. They found that many individuals failed to make full use of their potential after rehabilitation, particularly those capable of sheltered employment or simple work in non-sheltered employment. In a further study Najenson et al (1980) assessed the rehabilitation outcome of 147 subjects, the test being the subjects' reintegration into work according to their capacities. As with the previous study, they found that final employment results were affected mainly by the cognitive state and by behavioural disturbances as judged by social competence. The gap between the multidisciplinary team's expectations and the patients' actual functioning within the community was proportional to the severity of the injury.

There are very few published reports concerning the effectiveness of total rehabilitation programmes for head injured individuals. Both Cope & Hall (1982) and Hyunok et al (1988) have found significant relationships between length of coma and the length of rehabilitation hospital days. In the latter study, the length of rehabilitation days did not correlate with either functional or cognitive improvement. Although the majority of patients discharged were independent in activities of daily living, problems existed with employment, education, finances, and in relationships with friends.

Ability to return to work is sometimes used as the chief criterion of successful rehabilitation. Studies of predictive factors have included pre-injury, injury, and post-injury variables. Humphrey & Oddy (1980), in a review of the literature, established that an inverse relationship has been shown between severity of injury and subsequent return to work.

Head injured persons are frequently unable to consistently integrate, apply, and generalise existing skills. They may also be unaware of the nature of their limitations and have vocational aspirations which are determined by intact memories of pre-injury, sometimes high-level, capacities. There is frequently difficulty, then, in setting realistic vocational goals. Unfortunately, the nature and extent of a head injured person's deficits may not be immediately apparent to others, including potential employers (Kay & Silver, 1988).

Studies of employment outcomes of head injured persons have shown that cognitive and behavioural disturbances are a major problem. The poorest outcome is seen in those with these deficits, despite the fact they may have good locomotor and communicative functioning (Yarkony et al, 1983). van Zomeren & Van den Burg (1985) found in their study of fifty-seven patients that, for those with longer PTA duration, work was likely to be resumed at a lower level than pre-injury or not at all.

In a study of ninety-eight severely head injured individuals during the first seven years after injury, Brooks et al (1987b) found that the employment rate reduced from eighty-six per cent pre-injury to twenty-nine per cent post-injury. Those aged over 45, or in previous unskilled occupations, were at the most disadvantage. The presence of cognitive, behavioural and personality changes was significantly related to a failure to return to work.

Although there are comparatively few comprehensive studies of vocational outcome for head-injured persons, Wehman et al (1988) found that the following conclusions can be drawn from such studies: severity and type of head injury are determinants of post-injury employment potential; fewer than half of patients with moderate to severe head injuries are likely to return to work; and, since the typical head-injured person is a young male with a normal life expectancy, the economic responsibility of caring for these unemployed individuals falls on others. Oddy (1984) considers, however, that the rate of return to work even after severe head injury may be higher than studies based on specialist units or rehabilitation centres suggest.

Fraser et al (1988), in reviewing the literature on vocational re-entry, consider that there are problems in interpretation of the results reported. These include : different criteria for assessing head injury severity; standardised neuropsychological assessment not reported; the role of pre-existing conditions not taken into account; variability in the length of follow-up and use of intervention; return to work criteria not well described; and work experience and status at time of injury not considered in relation to outcome.

There may be cause for criticism relative to the general area of head injury research. Godfrey et al (1987) complain that the findings of case studies and uncontrolled follow-up studies have not been convincingly supported by the findings of studies using control comparison groups. Moreover, they consider that the

controlled studies have been both few in number and methodologically inadequate.

Oddy (1984) also refers to difficulties in the interpretation and synthesis of studies conducted into the outcome of head injury: sampling differences, differences in level of measurement of injury severity, selection of subjects treated at a single hospital or unit, variability of subjects' age range, varying intervals of follow-up, and variation within assessment measures.

Mild head injury

The foregoing discussion has concerned itself mainly with persons who have suffered moderate to severe head injuries. Although some of the studies described have used samples of subjects whose disabilities ranged from mild to severe, mild head injury per se receives relatively less attention in the literature.

Wrightson & Gronwall (1982) estimate that the incidence of mild head injury is about 50 per 10,000 of the population each year. Most are young men and most recover without complications. However, some ten per cent will have persistent, disabling symptoms, referred to as "the post-concussion syndrome". Jennett & Teasdale (1981) consider that there is an underestimation of the damage and aftermath of mild head injuries; there can be some structural damage to the brain even after brief concussion. As well, the effects of repeated concussions are cumulative.

Gronwall & Wrightson (1974) found evidence that persons who have suffered concussion are unable to process information at a normal rate for a period of time. As early as a week after the injury, symptoms of the post-concussion syndrome can be present. Subjective features are accompanied by objective changes in intellectual function and, as normal intellectual function returns, the symptoms regress.

In a follow-up study of 424 patients three months after minor head injury, Rimel et al (1981) found that the majority had persistent headaches and more than half had memory problems. A third of those who had worked pre-injury were now unemployed. Neuropsychological testing demonstrated some problems with attention, concentration, memory or judgement in most of those tested. Emotional stress caused by persistent symptoms was also apparent.

Wrightson & Gronwall (1982) describe the elements of post-concussion syndrome as: detachment (a feeling of being different from usual); impairment (slowness, lack of concentration, poor memory); fatigue (tiring easily, irritability, and sensitivity to noise); localised symptoms (photophobia, blurred vision, tinnitus, dizziness, headaches); and, reactions to symptoms (fear, tension, anxiety, resentment, insomnia, neuroticism).

Even minor head injuries, then, may result in a measurable defect in brain function. How an individual reacts to the typical group of symptoms appears to depend on personality and coping ability (Allen, 1986; Hook, 1988; Lezak, 1978a; Wrightson & Gronwall, 1982).

Summary

Head injury is classified in various ways, according to the type of injury and the subsequent diagnosis of its severity. The incidence of head injury in several countries is about one in 500 of the population. The majority of head-injured persons are male and young. Approximately half of all head injuries are the result of road accidents. People with head injuries tend to come from lower socioeconomic groupings, and may have had prior experience of head injury. Pre-injury alcohol and drug abuse, and trouble with the law, is not uncommon. Following a sequence of stages in the recovery process, the patients often suffer from a range of deficits, including physical, cognitive, executive, and psychosocial problems. The patient's pre-morbid personality

may affect outcome. Specialised rehabilitation programmes are generally underdeveloped. Ability to return to work is usually inversely related to the severity of the injury. The effects of mild head injury can often be underestimated.

CHAPTER 3

THE FAMILY

This chapter examines the literature as it relates to the family and carers of head-injured persons. There is a clear inter-relationship with the preceding chapter but the focus changes away from the head-injured person and towards the family. The purpose is to provide a definitive background to the present research.

The role of the family

Advances in medical technology have meant that the survival rate of severely injured persons has increased relative to earlier decades. The patient will ultimately move from the treatment facility to another environment, usually back to the family.

Obviously, the survival of the family is crucial. There is a requirement for them to adjust to the permanence of the patient's disability, and maintain the family unit throughout this experience. Ideally, the family will participate in the patient's rehabilitation endeavours. Just as the patient requires support, so the family also has a need for the provision of support and services (Shellhase & Shellhase, 1980).

While some families cope better than others, those undertaking the care of a severely head-injured person usually need to adjust to both the physical results of the injury and its psychological/behavioural consequences. The burden can be severe, as has been shown in a number of studies which will be described.

Initial responses of family members to the injury

A head injury is never planned; there is no time for the family to prepare themselves for subsequent events. The crisis is

compounded by being away from home and in an unfamiliar hospital environment. Mathis (1984) comments that a brain injured person may be unable to respond to family members at all, or may respond inappropriately and uncharacteristically.

Based on a study of 180 families in hospital and rehabilitation centre settings, Bray (1977) has described reactive patterns in families of the severely disabled. There are three stages, the first of which is the anxiety stage: the initial reaction of a severely injured person's family is fear. Relief is expressed when they find that he or she is still alive. The residual anxiety, however, may produce an obsession with the care of the injured family member. Anxiety is heightened because of strange medical terminology, and frustration occurs over ignorance of the injury and prognosis. Families may question the competency of staff and quality of patient care. When families are given conflicting information, increased stress and unrealistic expectations may occur. There is difficulty in assimilating a prognosis of prolonged recovery period and possible permanent disability. Denial of this reality takes many forms. Depression is common. The subsequent two stages are acceptance and then assimilation, with the acceptance stage lasting from ten months into the second year. The study did not relate specifically to families with head-injured relatives but has obvious applicability.

Rasie (1980) interviewed thirty Intensive Care Unit patients and their family members. Three recurring themes were identified: the need of the family member to relive the critical incident leading to the patient's ICU admission, a general fear of criticising the staff, and the desire for medical information together with the uncertainty about obtaining it.

An investigation into the needs of families in the immediate acute period following the relative's injury (not necessarily head injury) was carried out by Mauss-Clum & Ryan (1981). These were identified, in rank order, as: kind and clear

explanations, discussion of realistic expectations, emotional support, financial counselling, and resource counselling. A relative or friend and the physician were perceived as having been the most helpful in providing emotional support at the time of the injury. A common theme in both the Rasie and Mauss-Clum & Ryan studies was the desire by families for information and explanations. There is indication, however, that stress may result if the information is conflicting or confusing, while there can be uncertainty about how to go about obtaining the information.

Similarly, Mathis (1984), using a questionnaire designed by Molter (1979), found that, following the injury, the ten most important needs of family members of head-injured patients were, in rank order, to: feel hospital personnel cared about the relative, know they would be called at home if his/her condition changed, know exactly what was being done, have questions answered honestly, be told about medical treatment, receive daily information about the patient, feel accepted by hospital staff, feel there was hope, and have specific facts about the patient's progress. The rank ordering by head-injured individuals' families differed from those of two other non-head injury groups, particularly in that the other two groups felt that "to know there was hope" was the most important need. It is not clear why this was so.

A number of other studies have been conducted into the reactions and needs of family members following head injury trauma. Romano (1974) found that denial was strong and protracted, and there was very little evidence of families moving through the subsequent stages of the well known "grieving cycle". The degree of the denial, and its various forms, had repercussions for the adjustment of both patient and family. Bond (1983) comments that the common and natural response of denial may continue for many months into the process of recovery. It is shown by the way changes in the patient are ignored or excused. One practical consequence of family denial is that family members can become

hostile towards medical staff because of an imbalance of expectations between the two groups.

A "Command Performance Syndrome" in family members of severely head-injured persons has been described by Sbordone et al (1984). Significant others of the patients appeared to be relatively calm and emotionally controlled in the presence of the patient and professional staff. A self-report inventory showed more subjective distress than a control group, but scores were closer to normal controls than psychiatric outpatients. However, virtually all of the sample of forty-one later confided that, although they made the effort to appear "strong" in the hospital, they "fell apart" at home and were typically unable to sleep.

Later responses by the family

Family members frequently experience frustration because of variability in both the effects of head injury and subsequent recovery rates. Definitive answers may not be available for months and sometimes years. Crises during the recovery process may centre around the family's need to accept that many of the patient's physical and cognitive functions may never return (Rogers & Kreutzer, 1984).

Bond (1983) states that family members slowly begin to appreciate the full extent of changes in their family member, and to react to them. Depression and despair can develop at any time. Attempts to mourn are thwarted because the "mourners" have "the body" with them. In his experience, most family members separate emotionally from the disabled person between one and two years from injury; this permits a realistic view of the level of disability and development of social and emotional coping strategies.

Head-injured persons may suffer from mobility problems, sensory loss, cosmetic and orthopaedic deficits, and cognitive impairment, as well as personality change. They are often dependent on

relatives for their care (Livingston, 1986). Families may have little comprehension of how stressful the post-discharge experience may be; they receive little or no training. The family faces financial difficulties, radically altered family roles, and an uncertain future. The prolonged dependency of the head-injured family member can be an exhausting and unrewarding experience. The marriage relationship can change from a partnership to one involving dependency and supervision. Children may experience difficulty in understanding their head-injured parent's emotional and behavioural changes; attention required by the head-injured person may result in children feeling unintentionally neglected and insecure. Family members frequently report being depressed and overwhelmed. Disorders of mood occur, particularly anxiety, and normal social roles may be difficult to fulfil (Bond et al, 1979; Livingston, 1986; Mauss-Clum & Ryan, 1981; Oddy et al, 1978a; Rogers & Kreutzer, 1984).

Stages of reactions

Lezak (1986) has conceptualised a series of post-hospitalisation stages that describe the typical reaction patterns of families with a head-injured member. There are six stages and some experience the stages at different rates or even in different order. Others may bypass some stages, or be "stuck" in an early stage. The stages can also overlap, and shift back and forth.

Stage 1. Post-hospitalisation: 0-1 to 3 months. Perception of patient: a little difficult because of fatigue, inactivity, weakness, and so on. Expectation: full recovery by one year. Family reaction: happy.

Stage 2. Post-hospitalisation: 1-3 to 6-9 months. Perception of patient: not co-operating, not motivated, self-centred. Expectation: full recovery if he or she will try harder. Family reaction: bewildered, anxious.

Stage 3. Post-hospitalisation: 6-9 months to 9-24 months; can continue indefinitely. Perception of patient: irresponsible,

self-centred, irritable, lazy. Expectation: independence if know how to help him/her. Family reaction: discouraged, guilty, depressed, going crazy.

Stage 4. Post-hospitalisation: 9 months or later; can continue indefinitely. Perception of patient: a different, difficult, childlike person. Expectation: little or no change. Family reaction: depressed, despairing, "trapped".

Stage 5. Post-hospitalisation: 15 months or later; usually time-limited. Perception of patient: a difficult childlike dependant. Expectation: little or no change. Family reaction: mourning.

Stage 6. Post-hospitalisation: 18 to 24 months or later. Perception of patient: a difficult childlike dependant. Expectation: little or no change. Family reaction: reorganisation - emotionally if not physically disengaged.

Lezak considers that even psychologists who understand how head injury affects families can only assist them through these stages. The reactive process itself cannot be avoided.

The role of carer

Mothers and wives are the most frequent adaptors to the role of carer; the majority of head-injured persons are male. Assuming the role of parent to one's parent or spouse, or resuming the parental role with a formerly independent adult child can be a very disruptive experience (Lezak, 1978b).

Rosenbaum & Najenson (1976), in their study of wives of severely brain-injured soldiers, found that if the patient was married there was frequently conflict between spouse and parents. There was a tendency for each to become jealous and possessive of the head-injured individual. A study by Thomsen (1974) suggested that mothers adapt more readily than wives to family changes

resulting from head injury. Mauss-Clum & Ryan (1981) found some support for Thomsen's finding. Their sample comprised thirty primary family members (wives and mothers). Of the nineteen wives, one third had considered divorce, or were filing for it. The researchers comment that mothers do not have this option and it is more likely that they will have a life-time commitment to caring for the patient. Both wives and mothers were concerned about the welfare of the patient should they become seriously ill or die.

In a study of thirty head-injured subjects, Panting & Merry (1972) found that, following the head injury, the husband/wife relationship was less stable than the parent/child relationship. Of the ten subjects who were married at the time of the injury, four had subsequently divorced, and one had separated. The researchers commented, however, that two factors may have accounted for the apparently more stable pattern in parent/child relationships: in all but one of the cases, both parents were alive and thus the couples had each other for support; additionally, the average age of subjects living with their parents was twenty-six, while that of those living with spouses was forty. Recovery from brain injury is usually more complete in the young head-injured person. Bond (1983) comments that his experience of divorce in relevant head-injury cases is lower than that reported by Panting & Merry.

In a further study relative to divorce, Walker (1972) followed up 195 men who had been injured twenty-five years previously during World War II. Twenty-five per cent were not married and these tended to represent the most severely disabled subjects. Only eleven per cent of those who had married had subsequently divorced, compared to twenty-five per cent of the general population. However, Walker provided no details of the relative proportions of pre-injury and post-injury marriages.

Conversely, Jacobs (1988) studied 150 families with severely

head-injured members. The injuries had been sustained one to six years previously. In his sample, only about one-third were married at the time of the injury. However, the percentage of divorced or separated individuals in the total sample increased from 6.5 per cent pre-injury to 10.8 per cent post-injury - an increase in divorce or separation of sixty per cent.

Mauss-Clum & Ryan (1981) reported that the wives in their sample had experienced frustration, irritability and annoyance. More than half reported feelings of depression and anger. There was a decrease in time for themselves, and financial insecurity. Nearly half the sample endorsed a statement "I'm married but don't really have a husband".

While divorce can be considered to be an indicator of spouses' stress, it is nevertheless a relatively crude measure and does not take into account other variables such as the pre-injury functioning or length of the marriage. Additionally, it is not clear from the studies at which stage post-injury the decision to divorce was made. Divorce may represent the resolution stage of a reactive process, or may occur reactively during relatively early post-injury periods.

In contrast to the other reported studies, Livingston et al (1985) measured the level of perceived burden by wives and mothers of head-injured men in the first year following the injury. Although wives' perception of burden became apparent at six months and persisted through to the twelve month stage, compared to modest improvement in mothers' perception of burden, there were no statistically significant differences when comparisons were made of the three, six and twelve months assessments. Similarly, Brooks et al (1987a) studied a group of 134 patients and their relatives during a period of two to seven years after severe head injury. They found no difference in the distribution of high and low burden in mothers/fathers compared with husbands/wives. The distribution of burden scores was then compared between wives and mothers; more mothers than wives

showed higher levels of burden, but with insignificant results.

Lezak (1978b), in reporting of the experiences of over 200 families with head-injured members, comments that "feeling trapped" is a common experience. The caretaker's own needs may become submerged by the needs and demands of the patient. Isolation is also a problem. Some patients may require full-time attention, while others experience difficulty outside the home or with strangers. A sense of isolation may be exacerbated by withdrawal of support by the extended family. Outside relatives may be critical of the caretaker, perhaps perceiving the person as being too protective or restrictive, or too neglectful and uncaring. Family members may be abused by the patient: caretakers can become the focus of the patient's bitterness and humiliation.

Lezak reports that spouses have additional problems: the carer may live in a "social limbo" because of loss of a social partner; the spouse cannot mourn decently and does not have the support and comfort provided to the bereaved; there is reluctance to divorce because of previous bonding to the patient, a sense of responsibility, guilt, or fear of social disapproval; and sexual and affectional needs are frustrated. Head-injured parents may compete with their young children for the caretaker's attention, or ignore them. The caretaking parent can thus experience conflict over divided loyalties and responsibilities.

Subjective distress and perceived burden

A major cause of stress to the family following head injury is the personality change in the patient. The most frequently reported changes are emotional, motivational, and behavioural (Klonoff & Prigatano, 1987).

McKinlay et al (1981) reported on interviews with close relatives of fifty-five severely head injured adults at three, six, and twelve months after injury. The purpose was to obtain

information about psychosocial changes in the patient. The problems most frequently reported were patients' emotional disturbances, poor memory, and subjective symptoms, with physical disability much less common. The degree of stress experienced by relatives did not diminish between three and twelve months and was related to the incidence of mental and behavioural changes in the patient.

Following on from the McKinlay et al (1981) study, Brooks et al (1986) studied the same sample population at five years after the injury. The patients continued to experience psychological and behavioural problems, accompanied by minor physical deficits. The relatives were under great strain, significantly more so than at one year. The best predictor of strain in the relative was the magnitude of behavioural and personality change in the patient.

Livingston et al (1985) conducted a similar study with fifty-seven severely head injured patients and their female relatives, also at three, six and twelve months after the injury. Relatives were found to have significant and persistent psychiatric and social dysfunction and felt burdened in caring for the relative throughout the twelve months of the study.

At seven years post-injury, levels of relatives' distress can still be high. The effects of severe head injury on a group of 134 patients and relatives were examined from two to seven years after injury by Brooks et al (1987a). In the patient, disturbances of cognition, affect, and behaviour were very prevalent. Relatives reported high levels of distress or "subjective burden". The levels of the relatives' distress related to the type and magnitude of behaviour change in the patient. Relatives reporting unmet needs were particularly prone to high levels of burden. Prediction of burden in the relative was not related to the magnitude of the injury, or even the type of change in the patient, with the exception of the patient's emotional changes. The researchers suggested that

subjective burden arises not only from "without" but also from "within" the relative herself.

Other researchers have also suggested that the pre-morbid personality of the carer may well mediate subsequent events (Livingston et al, 1985; Oddy et al, 1980). McKinlay & Brooks (1984), using a modified version of Eysenck's personality scale, found evidence that relatives' personality is related to the reports they give. However, they felt that the extent of the influence of personality is not overwhelming when other factors are considered.

Overall, it appears that there is not a simple linear relationship between objective severity of the injury per se and the level of distress reported by relatives. Rather, Bond (1975) demonstrated that only some of the more prevalent psychosocial changes were related to injury severity. However, when the length of PTA is greater than four weeks, patient changes are likely to be many and their combined effect can have severe impact on the family (Brooks, 1984).

There have been other studies of patients and families during periods up to two years after the injury. (Oddy & Humphrey, 1980) found that family relationships appeared to have settled down by the two year point but social contacts were still less frequent. Personality and cognitive changes in the patient were associated with relationship and social difficulties. Premorbid personality and physical deficits were associated with time taken for patients to return to work. Rosenbaum & Najenson (1976) compared wives of head-injured patients with wives of paraplegics and normal controls, at one year after the injury. In comparison to the other two groups, the wives of head-injured patients reported their husbands as more self-centred, childish, demanding and dependent. The husbands played a lesser role in family responsibilities, including care of the children. The wives reported increased depression, significant loss in their social lives, and a reduction of sexual activity. There was a

tendency for these wives to report a feeling of dislike towards any physical contact with their husbands whom they now viewed as changed persons. The findings, however, were based on a relatively small sample.

Oddy et al (1978) reported that the worst period of stress for the majority of relatives of head-injured patients was during the first month after the injury. The level of stress appeared to level off by the sixth month and no further diminution was found at twelve months. Stress appeared to be mediated by relatives' perception of personality changes and subjective defects. It was not affected by the objective severity of the head injury or associated disabilities, nor by whether the patient had resumed work and leisure activities.

Thomsen (1974) found that nearly all of the relatives in her sample complained of change in the patients' personality and behaviour. The most common changes were reported as irritability, hot temper, lack of spontaneity, restlessness, emotional regression, emotional lability, and stubbornness. Pathological laughter was also a problem to many relatives, so much so that they tried to isolate the patient from strangers. The swearing of a severely aphasic patient provoked a similar reaction. In a further follow-up study, Thomsen (1985) found that behavioural and emotional difficulties in patients still constituted stress for relatives ten to fifteen years post-injury.

Livingston (1987), in a study of forty-two mild head injury patients and fifty-six severe head injury patients, confirmed other studies which have reported that the relatives' burden following head injury is not always related to severity of injury. He speculates that, since many relatives complain of inadequate or poorly communicated information from medical personnel, it is reasonable to consider that relatives' perception of the injury may not relate to objective criteria.

A number of the previously described studies have not used control groups. O'Brien (1987), using control groups, found that mothers of head-injured patients - relative to ratings of anxiety, depression, or emotional distress - did not differ significantly from mothers in two comparison groups. The latter two groups comprised mothers with orthopaedically-injured offspring and a "non-injury" control group. However, mothers of head-injured individuals reported greater psychosocial dysfunction in the patients than did mothers in the other two groups. There was no difference in the two "injury" groups relative to perceived physical dysfunction in the patients. The period of time elapsed since the patients' hospital discharge ranged from one to four years.

Family rehabilitation, therapy, and support

There is general agreement amongst researchers of the need for the family to be fully included in the rehabilitation of the head injured person. Essentially, it is the family unit itself that needs rehabilitation. However, if the family is to play such a role, adequate preparation, information and support must be provided. Unfortunately, this is often lacking.

Bond & Brooks (1976) consider that the difficulties encountered by the families of head-injured persons have a significant effect upon the rehabilitation process, particularly in the late stages of recovery from head injury. They feel that the demonstrated variability in levels of reported distress by relatives may be reflected, at least in part, in the variability in the level of physical, mental and social restitution gained by patients who otherwise have similar degrees of brain damage.

Stewart (1985) comments that real success is achieved when the client and his carer make the rehabilitation programme their own. Relatives, since they are already so closely involved in the caring, need a great deal of understanding and support so that they can achieve a necessary degree of detachment and objectivity

during the rehabilitative process. The support provided to a relative from an understanding counsellor or therapist is likely to benefit both the relative and the disabled person for whom the relative cares.

The need for family support and guidance is not confined to head injury groups. Davis (1980) conducted a study into the dynamics of caring for a disabled (not necessarily head-injured) adult in the home. In terms of acclimatisation to misfortune, the thirty families in her study had experienced maximum change during the initial stages of home care (disorganisation, panic, self-blame, rationalisations, busyness, and overwork). During this period they had enormous need for support, guidance and services, which in many instances were not met except within the family itself.

Livingston et al (1985) consider that their research into the impact of head injury on relatives has clearly demonstrated the need for support of relatives after head-injured patients are discharged home. Such help involves personal support for carers themselves and the provision of guidance to carers in managing patients. Carers can well be viewed as potential full-time non-professional therapists. Similar comments have been made by other researchers at the conclusion of studies of carers' stress over periods ranging from three months to seven years after the patients' injuries (Brooks et al, 1986; Lewin et al, 1979; Thomsen, 1974; Weddell et al, 1980).

A common complaint by families of head-injured individuals is that concerning lack of information when the patient is discharged from hospital. In a study by Thomsen (1974), almost half of the relatives said very little information had been given, particularly regarding neuropsychological sequelae. Many of the relatives had praised the intensive care in the acute stage, but felt there was much room for improvement of treatment and follow-up in later stages. Bruckner & Randle (1972); Crawford (1983); Lezak (1986); Panting & Merry (1972); and Romano (1974) have reported similar findings.

Information needs are not restricted to patients' prognostic indicators and management. Lezak (1978b) details "what family members need to hear":

- (1) Anger, frustration and sorrow are natural emotions for close relatives of brain injured patients.
- (2) Caretaking persons must take care of themselves first if they are going to be able to continue giving the patient good care.
- (3) The caretaker must ultimately rely on his or her own conscience and judgement in conflicts with the patient or other family members.
- (4) The role changes that inevitably take place when an adult becomes dependent or irresponsible can be emotionally distressing for all concerned.
- (5) The family members can probably do little to change the patient and thus need not feel guilty or wanting when their care does not result in improvement.
- (6) When it appears that the welfare of dependent children may be at stake, family members must explore the issue of divided loyalties and weigh their responsibilities.

In a study of head-injured men and their families, Livingston (1986) found that the majority were not making use of any rehabilitation facilities. There were follow-ups at neurosurgical head injury clinics, and a few patients received physiotherapy, occupational therapy or speech therapy. However, most of the relatives did not take up rehabilitation with the patients; a number of the relatives were receiving tranquillisers from their doctors. Only one relative received help from a social worker. The author commented that rehabilitation facilities in the United Kingdom are not well developed and there is great lack of facilities offering psychological management after head injury.

In a study in Los Angeles, Jacobs (1988) found that families reported themselves as being the primary source of therapeutic

treatment for the patient because there were insufficient programmes available. Although long-term professional services were expensive, lack of availability was more of a concern to families than cost.

Some families appear to have particular need for intervention. Rosenthal (1984) has described "high risk" families as being: those with a premorbid history of dysfunction or maladaptive interaction patterns; those where the patient demonstrates severe, chronic cognitive and/or behavioural deficits; and, families in which denial is used for a prolonged period. Intervention strategies include patient-family education, family counselling, family therapy, and family support groups. He suggests that family intervention should be considered as a primary mode of treatment in the comprehensive rehabilitation management of the brain-injured patient.

In the context of family therapy, a theoretical model has been developed by Perlesz & Furlong (1989). This model proposes that, following a head injury to a family member, the related tasks challenging the family are to: (a) restructure, (b) grieve, (c) develop a new identity through the crisis, and (d) achieve a sense of growth through the crisis. In the restructuring process, there is a re-arranging of the respective roles and responsibilities of family members. Roles may need to be adapted or radically re-modelled. Grieving may be difficult. It has a "false start". Unlike a death, losses may not be so easily identifiable, and extended duration of post-accident improvement also serves to constrain grieving. A new sense of identity is needed not only for the head-injured person but for the family as a whole. Achievement of a sense of growth involves attaching a positive meaning to the tragedy, while still acknowledging the losses.

Klonoff & Prigatano (1987) describe clinical intervention with families in terms of the following principles:

- (1) A close working alliance with families is essential for the successful rehabilitation of patients.
- (2) The nature of the frequent contact with relatives is both educational and supportive.
- (3) Families require clear definition of the goals of rehabilitation for the patient:
 - (a) independence
 - (b) productivity
 - (c) satisfying love relationships
- (4) Families must learn to adjust to the effects of brain injury and begin to reconstitute their own lives, just as patients do.
- (5) To adequately address the needs of families, there must be work done in both groups and individually.

Additionally, Klonoff & Prigatano consider that successful rehabilitation cannot take place only in the context of a rehabilitation facility; there is a need to generalise to the home, community and, when possible, the work place. There should be provision of feedback to the family regarding neuropsychological test results. Family members may be unaware that personality changes can be a direct result of brain injury; helping relatives to appreciate that these changes are, at least in part, organically based tends to reduce their confusion.

Oddy et al (1978a) comment that the past emphasis in the rehabilitation services has been a focus on physical disabilities, with social rehabilitation primarily geared towards re-training patients for work. Their research findings underline the importance of helping patients to readjust to family and social life as well as work. Marital and parental counselling needs to form part of the routine after-care of brain-injured patients.

Given that research has produced consistent findings that the psychosocial consequences of head injury are more distressing than the physical deficits, it is somewhat surprising that many

rehabilitation programmes continue to emphasise the physical rehabilitation of the patient while overlooking emotional social adjustment needs. This is especially so when one considers that the long-term goal, in most cases, is that of returning the patient to the family unit.

Vogenthaler (1987a) also refers to the need for a holistically oriented rehabilitation programme that provides educational and therapeutic services to family members. Relatives need to learn how to help the head-injured person, discover what benefits and services are available, and be taught how to handle problematic behaviours. Help is required for family members in dealing with fear, denial, grief, guilt, and unrealistic expectations. Once the formal stage of post-acute rehabilitation ends, family members are likely to benefit from training in patient therapy, an example of which is behavioural programmes.

A plea for holistically oriented rehabilitation programmes was made almost thirty years ago. Christopherson (1962) commented that it cannot be assumed that families will necessarily have the intelligence, values, education, motivation, or even the interest to enable them to proceed independently towards rehabilitation goals. Family resources may be limited, and thresholds of tolerance to frustration and crisis vary. Those families and individuals who barely cope under normal circumstances may find the additional burdens of caring for a family member with a disability more than they can bear. The rehabilitation focus, then, needs to have the family unit as its central rehabilitation goal.

Summary

The family's role is crucial relative to caring for the now disabled and dependent family member, and supporting him or her through the rehabilitation process. The family's responses in the immediate post-injury period are characterised by shock, denial,

a desire for information, and a need for support. The post-discharge period is typically very stressful for the family. Initial optimism tends to gradually give way to a more realistic and detached perception of the changed family member. The burden on the family can be severe as they adjust to physical and non-physical changes in the head-injured family member. There appears not to be a simple linear relationship between the objective measure of the patient's injury severity, and the subjective level of the carer's stress. Carers are usually women. Spouses may experience more, or different sources of, stress than parents. Carers' levels of stress may still be high as long as seven years or more after the patients' injuries. Rehabilitation services are generally not well developed. There is a perceived need for holistic rehabilitation programmes with a family focus. Rehabilitation measures need to address the overall psychosocial problems, as well as the patient's physical difficulties.

CHAPTER 4

THE PRESENT RESEARCHRationale

Despite the fact that there has been a great deal of research into the general area of head injuries, relatively few studies have explored in depth the difficulties experienced by those caring for head-injured persons. This is particularly the case in New Zealand. A literature search located only two studies (Blyth, 1981 and Crawford, 1983) which had examined the outcome of severe head injuries in New Zealand samples. The focus, however, was on the patients, although family difficulties were noted.

Given the relative paucity of studies, there is a continuing need for research relative to the families and carers of head-injured persons. The importance of the role of the family in the rehabilitation of the head-injured person is widely recognised. Obviously, the greater the degree of the patient's disability, the more he or she depends on the family. The family also has an important role to play in the head-injured person's ongoing rehabilitation. Rosenthal considers that "..... physical rehabilitation may be of little consequence if the patient cannot be successfully integrated into the family unit and regain useful function within society" (Rosenthal, 1984, p.228).

Aims

The literature reviewed in the preceding chapters provided impetus and direction for the present research. The present study expects to build on the findings of other researchers. It is the intention to explore, in depth and breadth, the psychosocial consequences of head injury from the perspective of persons in the caring role. Research questions will address carers' needs and what is required to meet those needs (for example - medical support, information, after-care facilities, psychological

counselling, family assistance, support groups, and friends/confidantes). Analysis of results will consider individual data as well as the patterns and themes apparent in the respondents' grouped data.

The primary aim of the present research, then, is to:

- (a) gain insight into the "world" of those caring for head-injured persons in the New Zealand community
- (b) identify carers' major areas of stress
- (c) explore carers' support needs

Two secondary aims are to:

- (1) examine the findings in the context of previous research in the area of the families and carers of head-injured persons
- (2) provide information which may be of practical use to those involved in, and planning for, the rehabilitation of the family unit following serious head injury to a family member.

Research design

A cross-sectional multiple case-study design is chosen, with emphasis on qualitative rather than quantitative data. An interview protocol will be used to gather qualitative data, although a verbally-administered questionnaire will ensure the collection of quantitative data by means of standardised questions to be asked of all respondents. Details of the questionnaire are provided in the Method chapter. It is hoped that this latter standardised approach will add to the reliability of the obtained data.

Quantitative measuring instruments alone are seen to inherently limit the range of available responses and restrict the range of

experiences and events to be measured. Additionally, because of the sensitive nature of the research, it was not seen as appropriate that instruments such as mail questionnaires be used.

Essentially, the approach will be exploratory, descriptive and hypothesis-generating. There will be a search for patterns and themes within and between the studied participants, and these will be systematically described. The search will place within the context of respondents' "real lives". Data reduction will take the form of reported frequencies and occasional references to measures of central tendency. The responses to closed questionnaire items will be displayed in the form of tables. Patterns in the case studies will be identified by reporting the frequencies of recurring themes. This type of approach is recommended by Miles and Huberman (1984), p.21.

Yin (1984) has described a case study as "an empirical study that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used." (p.23).

Bromley (1986) views a psychological case study as "an account of a person in a situation" (p.1) and "the usual purpose is to find a solution to the person's problem." (p.2). He states that:

"By comparing and contrasting cases, a kind of "case law" can be developed. Case-law provides rules, generalisations, and categories which gradually systematize the knowledge (facts and theories) gained from the intensive study of individual cases" (p.2).

Support for qualitative measurement is provided by Fielding & Fielding (1986) who comment that qualitative data are "rich" or intensive and that the vivid material obtained is useful in evaluating an analytic framework (p.44). The qualitative and quantitative approaches are thus complementary and can be inter-

linked.

The research design chosen for the present study, then, encompasses real-life situations, provides multiple sources of evidence, seeks solutions to problems, helps develop "case law", and provides "rich" material for evaluating analytic framework.

Expectations

Since the present study is exploratory in nature, no definite hypotheses are held. The present study's focus on in-depth case studies is not unique and has been used by other researchers studying families of head-injured persons. Expectations are indicated in the current literature reviewed in earlier chapters.

It can be reasonably expected that there will be common patterns associated with both individual and group subjective perceptions of: (a) the head-injured family member, (b) role relationships, family interactions, family lifestyle, and carers' wellbeing, and (c) the quality of professional, personal and practical support received and/or required.

These variables have been identified in previous research as being contributors to a carer's perceived level of distress. In the present study, these same variables will be examined by means of standardised questionnaire items, so that their relevance in the present sample can be identified. Additionally, it is anticipated that descriptive data collected during the semi-structured interview will identify other variables which may play a role in mediating stress in the present sample of carers.

CHAPTER 5

METHODSample

The sample for this research was obtained through the Medical Rehabilitation Unit of the Palmerston North Public Hospital. Summarised details of this rehabilitation facility are contained in Appendix A. With prior permission from the Ethics Committee of the hospital, the researcher discussed details of the research project with the Acting Director of the Unit; a copy of the proposed questionnaire was provided. Agreement was obtained that head-injured patients and their caregivers would be contacted by the Unit to see if they were willing to participate in the research.

The researcher's criteria were that: (a) the patients lived within reasonable travelling distance of Palmerston North, (b) that the head injury had been experienced more than six months previously, and (c) as much heterogeneity as possible was obtained relative to age, family composition and circumstances, ethnicity, geographical location, and socioeconomic groupings. The sample, then, was not a randomly selected one.

Written contact with selected patients and their caregivers was made by Rehabilitation Unit staff; details were provided of the research project and the researcher, and assurance was given of the confidentiality of obtained information. Those agreeing to participate in the research did so by signed acknowledgement. The participants were also requested by Rehabilitation Unit staff to provide signed consent for release of information. Information provided to the researcher from patients' medical files was restricted to: (a) condition as at hospital admission, (b) length of hospitalisation following injury, (c) length of post-traumatic amnesia, (d) assessment of severity of the injury (based on PTA), and (e) resulting disability.

Given that all the patient sample had been treated at the Rehabilitation Unit, it was anticipated that all the subjects would have severe head injuries. This was the case. All the subjects had experienced PTAs of longer than seven days, many of them much longer. In discussion with the Acting Director of the Rehabilitation Unit, it was decided to group the sample into convenient categories of "severe" (less than four weeks), "very severe" (four to eight weeks), and "extremely severe" (greater than eight weeks). While this does not follow precisely the conventional groupings where "very severe" is one to four weeks, and "extremely severe" more than four weeks (Jennett & Teasdale, 1981), it provided a means of describing the relative within-group severity of injury. The PTA details for each patient subject were obtained from their medical records. Individual details are reported in the case studies. PTA was used as the measurement of severity since only a few of the patients' medical records contained details relative to the Glasgow Outcome Scale.

A final sample of eleven people was chosen by the researcher from a total of thirteen respondents. Heterogeneity relative to ethnicity and family composition was not as well represented as had been hoped. For example, none of the head-injured subjects was a married woman; all of the carers were Caucasian; and all the main carers were women, although there was shared responsibility with their husbands in two cases. One of the subjects was Polynesian; he had lived in New Zealand for over twenty years. In terms of family composition, none of the subjects lived with siblings.

Materials

A copy of the 85-item questionnaire instrument is presented in Appendix B. During a literature review, the researcher became aware of studies conducted by Professor Neil Brooks (and others) of the University of Glasgow. These studies had examined the effects of head injuries from carers' perspectives. Professor Brooks kindly sent the researcher a copy of the

questionnaire (checklist) used in his studies (refer Appendix C). Reliability studies had shown the instrument to be highly reliable (Brooks & Aughton, 1979). Professor Brooks subsequently gave permission for the researcher to incorporate parts of the instrument into the present questionnaire.

Some items needed to be modified for the New Zealand context; the question relating to subjects' moods and behaviour was reworded to avoid "leading" respondents. It was also decided not to use the original "personality" scales, but to obtain pre-injury and post-injury ratings relative to the "moods and behaviours" questionnaire item. Since only the carers were interviewed, there was no need for a patient subjects' section in the questionnaire. As well, the original 7-point rating scale for relatives' distress was amended to an 10-point scale in the present instrument to permit a more sensitive range of responses in the present sample.

The original Glasgow instrument was designed around three conceptual measures: Type 1 objective burden (changes in family routine, family health, housing conditions, financial status, and social and leisure activities); Type 2 objective burden (post-traumatic symptoms and changes to the patient's behaviour and personality); and, Subjective burden (stress felt by the person caring for the patient, resulting from the presence of objective burden). The Type 1 burden represents changes forced upon the family, Type 2 represents changes and symptoms in the patient which can be assessed independently of relatives' reports, and subjective burden represents the stress felt by the carer, which is less easy to measure (Brooks, 1984c). These concepts are retained in the present questionnaire.

Obviously, it was not the intention of the researcher to replicate Professor Brooks' much larger, longitudinal studies; however, it was felt that possible resultant patterns of similarity or differences in areas of carers' concerns would be of interest. Unlike Professor Brooks' studies, the patient

subjects were not interviewed.

The present instrument contains seven sections. The sections relating to "Historical", "Informant", "Accident", "Post-accident", and "Agencies/professionals" are relatively structured, although some supplementary descriptive information is called for. The remaining two sections of "Carer", and "Family occupation/s, income and life style", contain both structured and open-ended items. It was considered that the "Carer" section contained sensitive questions and should not be the final section to be administered to respondents because of the need to minimise their possible distress. It is thus the penultimate section of the questionnaire. The instrument was administered verbally to the respondents.

Pilot interview

The questionnaire and interview procedure were pretested with one randomly selected respondent prior to arranging interviews with the remaining participants. Before the interview commenced, the respondent was advised that this was a pilot procedure; she was asked to inform the researcher freely of any difficulties or perceived omissions with questions and general procedures. The respondent was satisfied with the questionnaire and interview and had no criticisms or comments to make. Similarly, the researcher experienced no difficulty in administering the questionnaire, recording descriptive information, and conducting the interview. With the respondent's permission, the researcher telephoned the respondent within a few days of the interview to establish if she had experienced any distress as a result of the interview, or had any further comments to add. The respondent considered that the interview had helped her "to get things off her chest" and felt that the interview had covered all the main issues.

The comprehensive questionnaire item relating to the subject's present moods and behaviour had produced one "other" response,

namely "aggression". Since this question had been deliberately constructed to avoid "leading" questions, it was decided not to incorporate "aggression" into the questionnaire item following the pilot interview. In the absence of apparent problems with the questionnaire instrument, it was decided to proceed with the main study without further pre-testing and also to incorporate the pilot interview in the main study.

Procedure

The researcher made initial contact with the caregivers by telephone to introduce herself and to arrange interview times. The respondents were advised of the likely time commitment that would be required; every endeavour was made to cause minimum inconvenience to the respondents. All the interviews were conducted in the respondents' homes. Only the caregivers were interviewed. In three cases there were joint interviews with the parents of head-injured subjects.

At the interviews, the respondents were informed of the confidential nature of the research, and of their right to decline to answer any questions or discontinue participation at any time. The respondents were assured that pseudonyms would be used in lieu of the patients' real first names, and that geographical location would not be recorded. The questionnaires were identified only by code numbers. Given the sensitive nature of the research, every effort was made by the interviewer to be as tactful and relaxed as possible.

At the interviews, it was emphasised that the questionnaire was essentially a "check list" which would be read out to all the participants in the study. Because of the qualitative nature of the research, the participants were encouraged to provide comments freely as the interview proceeded. The interviews ranged from 2.5 hours to 4.5 hours in length, with a mean of 3.5 hours. By arrangement, the researcher telephoned all participants within a few days of the interview to thank them

again for their participation in the research, ensure that no distress had been caused, and to enquire if the respondents had any further comments to add. None of the participants reported any distress; four of them stated that it had been very helpful to them to discuss the various matters. There were follow-up comments in only two cases, most participants feeling that the interview had fully covered the issues. None had declined to answer any questions and all respondents completed full interviews. Some of those interviewed were not aware of the head injury support group in Palmerston North. In those cases, the researcher provided the respondents with written information about the support group.

At the conclusion of the study, a summary of the overall group results was sent to each respondent by mail, and each was thanked again for participating in the study. Further details will be made available to respondents at their request. However, ethical considerations of confidentiality are of major concern. The individual case studies section of the present report will be omitted from any full reports made available locally to relevant agencies, personnel or the respondents themselves. Despite the use of pseudonyms, persons with local knowledge of individual cases may be able to identify the persons concerned.

For the purposes of this research, the interviewed carers are referred to as "informants" or "respondents", and the head-injured patients as "patients" or "subjects".

CHAPTER 6

RESULTS

The results are grouped into two sections: (1) "Questionnaire", and (2) "Case studies".

The first section provides a descriptive account of results from the questionnaire. Results are presented in sub-sections and under a series of relevant headings. The main areas are highlighted. Not every questionnaire item is addressed, and there is some clustering of inter-related results. Appendix D contains Tables 1 to 7. These detail quantitatively, in simple statistical form, the full data from the closed items of the questionnaire (frequency distributions and occasional measures of central tendency). For the purpose of clarity, the tables follow the same format as the questionnaire. Where the questionnaire items called for descriptive information, this is noted in the tables.

The second section contains the descriptive data relative to fully or partially open-ended questions. It also contains comments made by respondents during the course of the interview. Patterns and themes are identified by means of reporting frequencies within similar categories of responses. Eleven separate case studies are presented. They each contain an individual respondent's comments within the context of the relevant case study.

1. QUESTIONNAIREHISTORICAL DATA

Data for this section are presented in Table 1.

Time since injury

At the time of the interview, the number of years elapsed since the patients' injuries ranged from two to six years, with a mean of 4.3 years, and a median and mode of five years. Other studies have indicated that relatives' stress "levels off" by the sixth month and remains relatively constant thereafter (e.g. Oddy et al, 1978). Similarly, at five years post-injury, relatives' stress has been found to be similar to (or sometimes worse than) that experienced at one year (Brooks et al, 1986). The present results, then, should not have been unduly influenced by variations in the period of time since the patients' injury.

Gender, age, and marital status

Nine males and two females were represented in the head-injured sample and their ages at the time of injury ranged from 12 to 45. Both the median and the mode for age was 23. At the time of the injury, three of the sample were married, two were separated or divorced, five were single, and one was a school pupil. At the time of the interview, one of the married couples were living separately, and one subject who was separated at the time of the accident had subsequently become divorced.

Severity of injury

The severity of the injury was categorised by Rehabilitation Unit staff on the basis of length of post-traumatic amnesia (PTA). It was not possible to use the Glasgow Outcome Scale as a measure of severity as this scale had been recorded in only a few of the patients' medical records.

Pre-accident illness or disability

Pre-accident, none of the head-injured sample was suffering from a serious illness. However, two subjects had experienced single episodes of concussion during a period of three to four years prior to the injury, while another had experienced two concussion episodes in a similar time period. Another of the subjects had

suffered a stroke as a three-year old child and was still experiencing some right-sided weakness at the time of the accident. He had also had a tendency to brief "blackouts", now thought to be epileptic in origin.

Pre-injury occupations

These were represented by hairdressing (self-employment), farming (two self-employed farmers and one farm hand), horticulture, supervisory occupations (manual), clerical work, and factory work (unskilled). Years of work in the job ranged from two months to twenty-three years, with a median of six years. The relatively high proportion of farming and horticultural occupations (four in total) reflects the geographical area from which the sample was drawn.

Geographical location

The areas of residence were as follows: city (5), town (2), and rural (4). Of those who were living in a city at the time of the interview, one subject and the respondent had moved from an earlier rural residence.

Alcohol and drug use

Pre-injury, the head-injured sample confined alcohol use to social drinking (ten) or abstained (school pupil). One subject used occasional cannabis, another used prescribed asthma medication, but the remainder did not use drugs. It is to be remembered, of course, that the questions were answered by the caregivers who were able to respond only to the best of their knowledge.

Characteristics of sample relative to published epidemiological data

The present sample of eleven is a small one. Given this, however, similarities and differences relative to published epidemiological data are noted.

Similarities: more males (nine) than females (two); seven of the sample aged twenty-five or under at time of injury; eight of the subject sample injured in road accidents; all of those aged under twenty-five injured in road accidents; three of the sample with previous experience of head injury (concussion), and one with experience of a stroke as a young child; and, a trend in the sample towards manual occupations.

Differences: no known pre-accident drug or alcohol abusers; and, no known problems with police pre-accident. Only one patient had been involved with the police relative to post-accident offences.

INFORMANT

Data for this section are presented in Table 2.

Relationship to patient

The relationships of the informants to the head-injured sample were spouses (three), parent/s (seven), and companion (one). In the case of parents, interviews were conducted with both parents in three cases, and with the mother only in the remaining four cases. Where joint interviews were conducted, there was not always initial agreement between husband and wife concerning responses to questions; however, subsequent discussion produced consensus. At the time of the interview, the parents' median age was 56.5, the spouses' median age was 40, and the companion was aged 53. The median length of the three marriage relationships had been thirteen years as at the time of the accident.

Living arrangements

Three of the head-injured subjects were living independently; these subjects were the three who had been classified as having the least severe injuries in terms of PTA. Intermittent help and support was provided by parent/s in two of these cases, with

the third having relatively more parental supervision. In the latter case, the patient's social isolation was a key factor in the need for parental support.

Of the two head-injured subjects who lived with their spouses, children (aged twelve and fifteen in one case, and twenty-one in another) lived in the parental home. One of these households also had a live-in home helper. Where the subjects lived with parent/s, there was one case of a relative also living in the family home. The remaining two subjects lived (a) with a companion, and (b) in institutional care. The spouse of the subject in institutional care lived separately with the couple's child.

ACCIDENT

Grouped data for this section are presented in Table 3.

Circumstances of accident

Details of the accidents were provided by respondents and are described in the individual case studies.

Alcohol/drugs at the time of accident

Informants reported that some alcohol had been consumed by two of the subjects at the time of the accident (both road accidents). This was confirmed by medical records. One of these subjects had also been taking asthma medication.

POST-ACCIDENT

Grouped data for this section are presented in Table 4.

Patients' assistance/supervision needs

At the time of the interview, eight of the subjects were independently mobile, although one used a walking stick to aid mobility. Two of these mobile subjects required supervision.

Three were confined to wheelchairs and required assistance, one being so disabled that constant attendant care was needed for all aspects of daily living.

Physical problems

All of the subjects had experienced physical problems over the year prior to the interview. These are detailed in Table 4.3, in rank order of reported frequency. In one case, the patient's sense of smell had actually sharpened to a remarkable degree, rather than diminishing. In another, the patient's hearing had become extremely acute after the injury.

Intellectual impairment

The medical records indicated that intellectual impairment had occurred in all eleven cases, ranging from mild to severe.

Moods and behaviour

Respondents were asked to rate various categories of the subjects' moods/behaviour on a 10-point analogue scale according to (a) the "pre-injury person", and (b) the "post-injury person". This questionnaire section was carefully worded in an attempt to avoid "leading" questions. The "other" response category produced five additional items. These were: aggression ($n = 6$), anger and frustration ($n = 4$), inappropriate laughter ($n = 2$), decision-making ($n = 1$), and motivation ($n = 1$). The mean direction of change was subsequently calculated and the rank-ordered results are recorded in Table 4.4. One of the subjects was too severely disabled for the respondent to be able to report about many of the items in this section.

Post-accident police involvement

Although none of the head-injured subjects had been involved with the police before the injury, two had had police involvement post-accident. In one case, however, this was related to a court appearance on driving charges associated with the accident

itself. In the other, there had been two post-accident drinking/driving charges, together with the subject's involvement in a fire-bomb episode.

AGENCIES

Data for this section are presented in Table 5.

GP

Only two of the head-injured subjects had regular head-injury consultations with their GP. The remainder of the sample had either irregular contact or saw the GP only for medical certificates or repeat prescriptions. In two of the cases, contact had been so limited that the respondents felt unable to rate the quality of help and support provided. It should be noted that four of the subjects were still receiving ongoing care from Rehabilitation Unit doctors, and two subjects had received this care for up to two years after the injury.

Other agencies and personnel

Respondents were asked to rate the quality of help and support provided to the patient from these sources, according to a 10-point analogue scale. The results are detailed in Table 5.2. The length of this assistance after the patients' discharge is summarised in Table 5.3. The area of most frequently expressed dissatisfaction related to the absence of psychological counselling: this type of assistance had been provided for only three of the patients.

Housing alterations

Alterations to the home were required in five cases. The most extensive alterations related to the three subjects permanently using wheelchairs. In another case, some areas of an open-plan house had to be altered because of the patient's propensity to hyperactivity, associated with a tendency to not notice steps and stairs. One subject needed ramp access to the house because

of mobility problems. In two cases, only handrails were required. The Accident Compensation Corporation met most of the costs of these house alterations, although contributions were made by the family in two cases. Excluding handrails, the costs ranged from \$300 to \$91,000, with a mean of \$24,760 and a median of \$6000.

Home help and attendant care

Overall, informants reported that the level of assistance was sufficient for needs. However, two respondents reported that they had not received home help assistance following the patient's hospital discharge, although this was needed. They were not aware at the time that such help could be requested.

CARER

Data for this section are presented in Table 6.

Confidantes and friends

Descriptive details are provided in the case studies section of this report. Two respondents reported both a decrease in close and distant friendships and lack of satisfactory access to confidantes. Several respondents were aware that many people mean well but feel awkward in offering support. There was expressed appreciation of the head injury support group.

Carer's health

Three of the respondents had regular contact with their GP. The reasons given were all stress-related, medical conditions in two cases being exacerbated by stress. Another respondent, although not currently seeing her GP regularly, reported that she had developed stress-related asthma which appeared to be a "delayed reaction" to stressful events; this had subsequently disappeared following resolution of some of the problems.

Help and support from agencies/people

The results of this section are detailed in Table 6.5. Ratings

of the quality of the help provided varied according to each respondent's individual experience. The consistent areas of expressed dissatisfaction related to head-injury specialists, the absence of psychological counselling, and the lack of information about head injuries. Of the four respondents who reported satisfaction with information about head injury, two had received this through a recently formed local head-injury support group. Complaints about the specialists included reference to their lack of sensitivity, a perception that seeing the specialist was a "technical exercise only", and medical failure to warn one respondent about the patient's likelihood of epilepsy prior to discharging him home into her care. Respondents felt that there was a real but unmet need for professional family counselling. One respondent thought that this should extend to all relevant family members, including the parents of married patients. A mother of a head-injured patient mentioned that she had been constantly at the hospital with her son after his injury but her husband had occupational commitments. When the patient was discharged home, the father was relatively much less prepared than she was to cope with the changes in their son; considerable family stress had resulted but no psychological counselling was provided. Another respondent commented that she was "wary of professionals" and preferred to cope with problems in her own way.

In four of the ten relevant cases, there was also some expressed dissatisfaction with Accident Compensation Corporation Rehabilitation Co-ordinators. This took the form mainly of complaints about lack of personal support and lack of information about entitlements.

Two of the respondents were receiving regular relief care and were satisfied with the quality and extent of the assistance. Another respondent (relative to earlier experiences) felt that annual relief care was insufficient and that this assistance should be available on a monthly basis. One carer would like relief care but was not aware that it was available. The

remaining respondents realised that relief care was available but had not yet used the service.

The patient after the injury

All the respondents felt there had been some change in the patient in terms of the person they knew before the injury. Four stated there had been a major change. Comments about the changes, including those causing the most distress to the respondents, are contained in the case history section of this report.

Level of strain and distress

Respondents were asked to rate their strain/distress on a 10-point analogue scale. The results are shown in Table 6.7. Relative to the three head-injury groupings classified by the Rehabilitation Unit, the "severe" group had a mean of 7.7 and a median of 8.0; and the "very severe" group had a mean of 9.0 and a median of 10.0; the "extremely severe" group had a mean of 8.0 and a median of 10.0. For the total sample, the mean was 8.2 and the median 8.0.

Future changes

The respondents' expressed perceptions and concerns about possible future changes are contained in the case studies section of this report.

FAMILY OCCUPATION/S, INCOME AND LIFE STYLE

Data for this section are presented in Table 7.

Work

Four of the subjects were working in full-time occupations at the time of the interview, compared to ten in full-time work in the week prior to the accident. However, two were working in part-time or supervised light work occupations. Only one subject was

now in a job that had a similar level of difficulty as that held before the injury. Four subjects had not returned to work since the injury. Respondents reported that subjects' future work capacity had been severely adversely affected in nine cases; the reasons given included physical disability, physical and mental slowness, tiredness, low tolerance to frustration, loss of memory, and loss of concentration. The subject who was a school pupil at the time of injury was too disabled to return to any form of schooling. No housewives were represented in the sample.

Of the carers, two parents and one spouse gave up work to care for the patient, and one companion had reduced her hours of work. Two spouses had taken up employment since the patient's injury for financial reasons, although one of these felt that her job had also "helped to keep (her) sane".

Financial position

Respondents all reported no financial problems prior to the injury. There were now major problems in one case, and minor problems in four others. Nine of the subjects were supported wholly or partly by income from the Accident Compensation Corporation (ACC) or the Department of Social Welfare (DSW). Only one of the eleven subjects was not an ACC client; the reason was that the accident had occurred outside New Zealand. One subject was receiving a weekly benefit from DSW as an interim measure until he reached the age to qualify for weekly income from ACC.

Standard weekly invalids' benefits are paid by the Department of Social Welfare. The Accident Compensation Corporation provides weekly earnings-related compensation based on 80% of pre-injury earnings. In cases where pre-injury earnings had already been low for various reasons, a further reduction in income had added to carers' stress.

Additional expenditure resulting from caring for the patient

Ten of the respondents reported that additional expenditure had resulted in caring for the patient, or because of the patient staying at home. Details of the expenditure are contained in the case studies section of this report.

Leisure activities

All eleven subjects had changed their leisure activities since the injury. Similarly, seven of the respondents had changed their pre-injury leisure interests. The changes are described in the case studies section of this report.

Household routines

Two respondents reported that household routines had been upset because of the patient's injury. One respondent commented that when the subject experienced an epileptic seizure, "everything had to stop". The second respondent stated that disruption to household routines had become a way of life. In the year prior to the interview, no-one had needed to stay away from school or work to care for the patient.

Family roles and relationships

Descriptive details are recorded in the case studies section of this report.

Relationship/marriage

Descriptive details are recorded in the case studies section of this report.

Sexual relationship

This question was applicable in only three cases. One respondent reported that the sexual relationship had never been resumed after the injury because of her husband's physical disability. Another subject was now unable to carry through

the sexual act as before and experienced frustration and anxiety about "performing", although it was hoped that the present problems may be overcome. In the third case, the patient was much less interested in sex than before the injury. In the latter two cases, the spouses reported that they understood the problems and were able to accept the present circumstances.

Family unit

Descriptive comment is contained in the case studies section of this report.

2. CASE STUDIES

The following section contains cross-sectional case data. It has been organised into the following groupings:

- (a) Descriptive information provided by respondents in response to those questionnaire items which called for such description. For the purpose of clarity, headings are used which correspond to the relevant questionnaire items and the questionnaire number is detailed.
- (b) "Other comments" in which some of the free comments made by respondents during the course of the interview are reported.
- (c) Eleven individual case studies. Pseudonyms are used instead of the subjects' real first names.

Group patterns and themes are identified by reporting frequencies within the descriptive data. The more individual or unique responses are contained in the individual case studies where, along with the relatively more common responses, they can be viewed within a case-study context.

2.a Descriptive information from questionnaire items

Do you have as many friends (both close and distant) as you did before the patient's injury, or have they increased/decreased in number? (Q.45)

There is a great deal of variability in the comments relating to this question. They are contained in the individual case studies. Grouped data are presented in Table 6.3 (Appendix D).

Is the patient the same person you knew before his/her accident? (Q.48)

All the respondents reported a change in the patient, in four cases a major change. The most commonly reported changes (two or more respondents) were:

Speech/communication/interactional difficulties (6)
 Frustration (5)
 Anger (4)
 Loss of confidence/self-esteem (4)
 Memory problems (4)
 Severe physical disability (confined to wheelchair) (3)
 Aggression (3)
 Social restrictions/isolation (3)
 Lowered tolerance to alcohol (2)
 General unhappiness (2)
 Inappropriate laughter (2)
 Changes in eating habits (2)
 Loss of concentration (2)
 Changed attitude towards life and others (2)

There were, however, individual reports of subjects being "more compliant", "less volatile", "more quick-witted", "even sunnier than before", "sense of humour retained", "basically the same person", "still showing glimpses of the old character", "essence of the person is the same", and "comparisons are fading as acceptance of the different person grows".

Which changes in the patient have been the most distressing
for you? (Q.49)

The patients' changes causing the most distress to carers were both physical and psychosocial. However, there were more than twice as many reports of psychosocial changes than there were of physical changes.

Physical or neurophysical

Speech difficulties or loss (2)

Physical slowness (2)

Totality of disability (1)

Loss of mobility (1)

Epilepsy (1)

Choking fits (1)

Pain (1)

Cognitive/emotional/behavioural/social

Communication/conversation/interactional problems (5)

Social isolation (5)

Frustration (2)

Aggression (2)

Swearing (1)

Memory problems (1)

Loss of independence (1)

Alcohol problems (1)

Mental slowness (1)

Loss of decision-making ability (1)

General unhappiness (1)

Loss of sense of humour (1)

Lack of overall response to others (1)

Loss of good manners (1)

Changed role relationships (1)

Unrealistic occupational goals (1)

Totality of disability (1)

In only one case were the most distressing changes reported as being exclusively physical.

Looking into the future, do you foresee any changes in:
(Q.51)

The patient

Hopes that he/she will continue to improve (5)
Hopes that patient will become more independent (2)
Foresees patient becoming less independent (2)
He is making adjustments to changed life (institution) (1)
No real change expected (1)
Likely to become more withdrawn and morose (1)

The level of help and support presently being received by you

No change (7)
Less help and support now required (1)
Will need more if present situation changes (2)
Could not cope with less (1)

Your own role as the carer/s

No change (6)
Reduction if patient becomes more independent (2)
Reduction because patient now in institution (1)
Increase if patient becomes less independent (1)
Time limited (1)

If you have any particular concerns about possible future changes, what are they? (Q. 52)

Long term provision of care (6)
Patient's social isolation (2)
Patient's possible physical deterioration (2)
No particular concerns (2)
Present life style could change (1)
Patient's possible severe depression (1)
Patient's possible loss of present independence (1)
Loss of spouse to share caring role (1)

Has any additional expenditure resulted from caring for the patient or from the patient staying at home? (Q.76)

Transport (7)
 Patient's projects, activities, entertainment (3)
 Food (3)
 Power (heating) (2)
 Furniture and equipment (2)
 Costs of house alterations not met by ACC (2)
 Wear and tear on car (1)
 Loss of carer's wages (1)
 Purchase of vehicle/s (1)
 Holiday costs (time out) (1)
 Assisting patient with finances (1)
 Wheelchair damage to house (1)
 Laundry expenses (during period of incontinence) (1)
 Impulsive toll calls by patient (1)
 Nothing specific (1)

Has the patient changed his/her leisure activities since the injury? (Q. 77)

Ceased

Involvement/interest in sports (9)
 Reading (3)
 Social life (2)
 Use of car/bicycle (1)

Continues (supervision or modification of previous interests)

Swimming (2)
 Indoor bowls (2)
 Horse-riding (1)
 Tennis (1)
 Attendance at organisation (Lodge) (1)

Passive activities only now (2)

Reasons given for changes:

Physical handicap (10)

Loss of former friends (3)
 Loss of interest (1)
 Loss of motivation (1)
 Loss of concentration (1)
 Loss of confidence (1)
 Social withdrawal (1)

Have YOU changed your leisure activities since the patient's injury? (Q. 78)

No change (4)
 Changed (6)
 Increased (1)

Reasons for change

Patient's supervision needs (1)
 Patient's emotional/behavioural state (1)
 Patient's severe disability (1)
 Interests formerly the same as patient's (1)
 Life style has changed (1)
 Now "too much hassle" (1)
 Carer formerly worked, now more social outings with patient (1)

Have the previous roles and relationships in the family undergone change since the patient's injury? (Q.81)

Parental role resumed (5)
 Marital/relationship roles have changed, carer now dominant (4)
 Altered patient/children interaction (2)
 Relationships have improved (1)
 No change (1)

In your opinion, what effect has the injury had on the relationship/marriage? (Q.82)

No longer a partnership (2)
 Previously separated, now divorced (1)
 Destroyed it (1)
 Has suffered from loss of communication and loss of help (1)

In your opinion, what effect has the injury had on the sexual relationship between yourself and your partner? (Q.83)

Details of the responses are contained in the "Questionnaire" section. They are also included individually in the case studies.

In your opinion, what effect has the injury had on the family unit? (Q.84)

No real change (3)
 Has improved/strengthened it (3)
 Some effect (2)
 Less support given to patient from siblings (1)
 Lifestyle has altered (1)
 Family unit is split (1)

2.b Other comments (two or more respondents)

Lack of information about head injuries (8)
 Insensitive attitudes by others towards patient (6)
 Lack of family counselling (5)
 Lack of patient counselling (4)
 ACC not sufficiently caring or helpful (4)
 Patient considers himself/herself fortunate not be worse (3)
 Carer/s "resigned to lot" or self-reliant (3)
 Not enough concern for patient in hospital, especially general wards (3)
 Financial worries have caused stress (3)
 Physiotherapy unavailable or not helpful (3)
 Carer has changed own personality as result of experiences (2)
 Lack of support for family during patient's hospitalisation (2)
 Family not consulted prior to patient's hospital discharge (2)
 Wished patient were dead (following the accident) (2)
 Activities/social centre needed for head injured people (2)

2.c Individual Case Studies

ANN

Ann was driving her car at 7 a.m. one morning. The driver of another car went through two give-way signs and collided with Ann's vehicle. She was thrown through the windscreen by the impact and the rear-vision mirror caused major facial injuries.

Age at time of accident: twenty-three. Occupation: hairdresser (self-employed). Condition on admission to hospital: Unconscious. Severe facial/skull lacerations. Extensive depressed fracture left frontal area. Required neurosurgery to de-compress the fracture. Necrotic area of frontal lobe removed. Required plastic surgery to replace gap left in skull. PTA: three weeks. Categorisation (this sample): "severe head injury". Has mild intellectual impairment and slight inco-ordination of upper limbs.

The same person as she was before the injury?

The informant considered that there has been a change of personality. Ann was formerly her "own person", was introverted, and tended not to display emotion. She is now almost the opposite: she can be aggressive and she is inclined to talk too much and to interject when others are speaking. Ann is aware that this can be a problem and has asked for "feedback" so that she can learn more appropriate behaviour. Ann has also experienced a lack of confidence and needs to consult with her mother before being able to make decisions. Ann's mother commented that the change is not always distressing because Ann is actually "more compliant and easier to deal with than she used to be". She is now relatively "easy to mould".

Which changes have been the most distressing for the carer?

The respondent felt that her daughter's aggression was the major

factor resulting from the injury. She is also distressed about Ann's present social isolation and lack of friends in her own age group.

Possible future changes and particular concerns

Her mother hopes that Ann will continue to improve and the present problems with pronounced talking will diminish. Ann has been encouraged to be independent and, as she lives alone, the level of help and support needed by Ann's mother is not considered by her to be of concern. However, the informant foresees a need to encourage Ann to become even more independent, and to be able to "back off" without feeling guilty about this.

Ann's mother's particular concerns about Ann centre around her daughter's lack of friends and companions. She has become socially isolated since the injury. Ann was engaged to be married at the time she was injured, but her fiancé was unable to accommodate the changes in Ann and the engagement ended some months after the accident. There has been a loss of confidence on Ann's part because she not only feels different, but is also treated differently by others. Ann's mother commented that "people are very sympathetic to begin with and then treat the head-injured person like an imbecile because of personality changes". Ann's topics of conversation have tended to become much more limited as a result of her life narrowing down to work, home, and immediate family. Ann's mother considers that her daughter's occupation has been her "salvation" as her life would be even more lonely without it. Her parents include her as much as possible in their own outings but she needs friends of her own age group. She is "too old for youth groups" and, at the time of the interview, was not aware of the local head injury support group.

Leisure activities

Ann's former interests included netball, swimming, spectator sports, parties, and an active social life. Her interests are

now confined to work, home and immediate family. Ann's mother considered that this was the result of social withdrawal, loss of former friends, and loss of confidence.

Ann's mother has not found it necessary to change her own leisure activities because of the caring role.

Additional expenditure relating to caring for the patient

The respondent reported that this was not a problem.

Carer's confidantes and friends

The informant was able to confide in Ann about problems to a limited extent, and had a relative with whom she could talk over problems when this was needed. The respondent had not experienced any decrease in friendships from people of her own age group.

Family roles and relationships

Ann's siblings are less tolerant and more critical of Ann now. They leave her out socially but use her as a baby-sitter. She is eager to help them and give them gifts, as she did before her injury, but Ann's mother considers that they do not give Ann the support she needs.

Effects on the family unit

The respondent felt that there was some jealousy on the part of other family members relative to their perception of Ann receiving too much attention, concern and financial support from the parents. Ann's mother commented that they forget the earlier critical days and see her as now being reasonably recovered from her injuries.

Other comments

Ann's mother stated that lack of medical information following

her daughter's injury had been a source of anger and frustration. Two specialists had been involved (one in another city, and one locally) and their prognoses were different. One had made very negative pronouncements about Ann's future while standing at Ann's bedside. Her mother considered that this showed lack of sensitivity towards the patient; Ann was later able to recall parts of that conversation. Ann's mother's main source of head injury information was from a nursing friend in another town. She felt that this contrasted markedly with the full information she had received from her doctor when a close family member was terminally ill with cancer.

When her daughter was discharged home from the hospital and into her care, Ann's mother found it very difficult to cope with what she described as the "non-normal" manifestations of Ann's head injury, both physical and behavioural. Most of these early problems had diminished or disappeared but they had impinged markedly on the carer's "normal" world at the time.

Overall, the respondent felt that Ann was very philosophical about the results of her injury. She had recently read an article about the effects of head injury and commented that she realised she was lucky that the outcome had not been much worse. Her mother agreed.

BEN

Ben was on his way home from work on his motorcycle. He was hit by a car which had pulled out to overtake another vehicle. His cycle helmet was knocked off in the impact.

Age at time of the accident: twenty-three. Occupation: horticultural trainee. Condition on admission to hospital: Unconscious but responding to painful stimuli. Cerebral anoxia. Fractured left clavicle. Fractured left wrist. PTA: eight weeks. Categorisation (this sample): "extremely severe head injury". Has mild intellectual impairment. Decreased vision both sides. Dysphonia.

The same person as he was before the injury?

There are temperament changes. Ben now "rages at times" and there is a general impatience. In particular, he can be aggressive and angry towards his father, although he calms down quite quickly. Ben was a very easy-going person before his injury. He is not as happy as he used to be. There is frustration associated with his speech difficulties and problems in communicating. He is much more dependent now on reciprocal interaction with others, seldom taking the initiative. He has become socially isolated and has lost independence. There are episodes of depression although he can be "jollied" out of these reasonably easily. Ben was previously very health conscious but this has changed. He has a lot less tolerance for alcohol now. There were some earlier episodes of drinking too much but his parents' warning that he would lose his driver's licence had the desired effect. Ben also has a tendency to choking episodes which were very frightening earlier but the family has learned to cope with these. This problem restricts eating out, however. Additionally, there is a tendency for Ben to laugh inappropriately; this causes puzzlement and sometimes embarrassment to others.

Which changes have been the most distressing for the carer?

Ben's communication problems cause the most distress. He "can't communicate well enough to be sociable enough". His social isolation leads to frustration and then aggression. This was never the case before the injury.

Possible future changes and particular concerns

The respondent hopes that Ben will be able to move from his parents' home to one of his own and become more independent. His short-term memory is poor, however, and this may create problems with household management. Tasks such as cooking could be inherently dangerous if he was to forget to switch off appliances. A flatmate or companion may be necessary. Ben has not needed to budget since the accident and may have difficulty in coping with finances without his parents' ongoing support. Before his injury, Ben was widening his life-style. It is now very narrow. His mother sometimes worries about there being other or better options: for example, if he did not have his supervised occupation in a rural setting, there may be more opportunity for him to socialise. She commented, however, "with what sort of friends?".

The respondent did not foresee changes in the level of help and support she is currently receiving. As far as her caring role is concerned, she looks forward to Ben being more self-sufficient but recognises that "he is very vulnerable". She feels he has very little to look forward to. Although he has a supervised occupational interest, his mother commented that there is a "loss of momentum" and an absence of life goals and plans. The lump sum received from the Accident Compensation Corporation needs to be carefully invested so that he does not "fritter the money away".

His mother had particular concerns about the future regarding Ben's lack of companionship. She wonders what will happen to him when his parents die.

Leisure activities

Ben no longer rides horses, plays tennis, or plays rugby. He still swims. At present he is looking for other interests and hobbies. The respondent gave his physical disability as the reason for the changed leisure activities.

Ben's mother had also changed her own leisure activities. This was partly because of Ben's need for supervision in his self-employed flower growing occupation. She felt that her supervisory role helped to compensate to some extent for the loss of her former interests.

Additional expenditure relating to caring for the patient

Extra costs have related to transport and travelling, together with the expense of setting up Ben's self-employed occupational project.

Carer's confidantes and friends

The informant is able to confide fully in Ben about problems. She also has a close friend with whom she talks over problems occasionally. Only one close friend has been lost and distant friendships have increased through the head injury support group.

Family roles and relationships

The respondent commented that "everyone's fuse is a bit shorter now" and there was a problem with Ben "firing off a few rounds", especially with his father as the target. Ben's mother tends to assume the role of peacemaker. Ben is much more dependent on his parents than he was prior to his injury.

Effects on the family unit

The respondent felt that there has been some effect on the family unit although other unconnected events have also played a part - for example, her husband's occupational retirement.

Other comments

Ben's mother is a former nurse but commented that she "had never before experienced such inconsistency with the medical fraternity" as she did following Ben's injury. She said that she was never offered any information and she had to "go after" the doctors to get it. There appeared to be continual "buck passing". Input from staff members was inconsistent and confusing. She felt that specialists and doctors should be "more in tune" with the prognosis for recovery. Information should be provided to the family as a matter of their right to have this. Another major area of concern to Ben's mother was the lack of family counselling. This was really needed but never offered. She commented that it is really important to talk with someone outside of the medical and friends groups. At the time of Ben's injury, the local head injury support group had not been formed. The respondent felt that support from such a group would have been of immeasurable help to her at the time.

Ben had apparently used cannabis surreptitiously during part of his stay at the Rehabilitation Unit. His mother said that he was more placid and pliable while using the cannabis and that his speech had improved noticeably. Everybody concerned "had agreed that this was so". No explanation had been provided for the improvement.

Ben's mother commented that he had always been a deep thinker and this is still the case. She feels that he is clearly aware of his present situation and struggles to accept it.

CAROL

Carol was using a pedestrian crossing when she was knocked down by a car. She was living and working overseas at the time.

Age at time of the accident: twenty. Occupation: bank clerk. Condition on admission to hospital: Deeply unconscious. No response to painful stimuli. Large right frontal contusion. Decompressive frontal lobectomy. Small epidural haematoma. Fractured skull. PTA: nine months. Categorisation (this sample): "extremely severe head injury". Has general intellectual impairment (borderline intellectually handicapped). Also frontal lobe impairment. Severe cognitive difficulties. Inco-ordination of upper and lower limbs. Epilepsy, controlled by medication.

The same person as she was before the injury?

Carol's parents consider that she has changed in many ways since the injury. Carol was previously a very independent person but now needs assistance with many activities of daily living, including showering and dressing. Her motivation is very low and they consider that she would sit in a chair all day if not "prodded" into activities. Her concentration is now very limited. She can no longer pursue her former interests of reading and drawing due to concentration difficulties. She becomes frustrated very easily and her almost invariable reaction is to swear in a manner she never did before her injury. The swearing can be triggered off either by frustration or by certain people who tend to irritate her. She has become very open and friendly with strangers, effortlessly starting up frank conversations. Her parents consider that Carol is more quick-witted than before her injury and she "has an answer for everything". Her hearing has become very sensitive since the injury and she overhears conversations some distance away. She is co-operative with her parents, wanting to please them, but her parents said Carol was less than co-operative with staff at the

Rehabilitation Unit. When they asked why, she stated that, "There is nobody there I want to impress". Carol looks well and her former friends tend to make comments such as, "You'll be back at work soon", not appreciating the extent of Carol's disability.

Which changes have been the most distressing for the carer/s?

The biggest worry for Carol's parents is that they do not know what she will say next. Her swearing causes them great embarrassment. Her short term memory is also a problem. For example, she is unlikely to remember what she ate at the previous meal. They are sad about her loss of independence. She does not engage in the usual activities of young people of her own age. There seems little likelihood of a boyfriend or marriage.

Possible future changes and particular concerns

Carol's parents are hopeful of her further improvement. They do not foresee any changes in the level of help and support currently being received by them. They expect to care for her as at present until they are too old to continue. They feel that the advantage of her living at home is that she can do things in her own time and not be "pushed" as she would be in an institution.

Future concerns centre around how Carol will get on without her parents. They hope she can live independently but with sufficient help and support to manage, perhaps through the Intellectually Handicapped Society. The parents do not want Carol's siblings to have to take over responsibility for her.

Leisure activities

Carol's former great interest in reading and drawing has been given up. She has returned to horse-riding under supervision. She is unable to swim without supervision. She can no longer drive a car or ride a bicycle. The reasons given

for the change of leisure activities were physical handicap, loss of interest, loss of former friends, loss of motivation, and loss of concentration.

Her mother worked before Carol's accident. She gave up this occupation to care for Carol. There are now more family outings than previously as Carol's parents take her out as much as possible. Daily routines are frequently upset but the family considers that this has simply become a way of life for them now.

Additional expenditure relating to caring for the patient

Extra costs had been incurred relative to power (especially heating), some special furniture, purchase of an exercycle, loss of Carol's mother's wages, transport, horse riding activities, wheelchair costs, and some toilet articles. In this regard, it should be noted that Carol is not an AGC client. In most circumstances, the Corporation would meet many of the described expenses, including the loss of Carol's mother's wages.

Carers' confidantes and friends

Carol's parents still confide in her fully about problems. They have each other for support, and discussion about problems. There has been a decrease in both close and distant friends. The parents feel they "know who (their) true friends are now". Although they understand why friends have been lost, it is still hurtful.

Family roles and relationships

Carol's mother feels she has become closer to Carol since giving up work to care for her. The former parental role has been resumed. The parents feel that this has not been too difficult to accept. Carol's father has retired and is able to help his wife with responsibility of the caring role. There have been times of stress and strain and of being "stretched". Carol's parents commented that a lot of patience has been required and that

Carol's progress following the injury has been long and slow.

Effects on the family unit

The family unit has always been a close one. Carol's siblings accept her as she now is. However, their mother is conscious that Carol's injury affected the other family members because of a period when the mother spent all her time with Carol. The other children are all married with children. In general, Carol's parents feel that their marriage and the family unit have been strengthened since the injury. As they put it, they "have all come to realise how vulnerable each of us is".

Other comments

Carol's parents felt they needed more information about head injury than they received. They were never really sure who they could ask. In many ways, they felt they were pushed from "pillar to post" as Carol was in two different hospitals following her injury. Carol's parents feel they required a "handout booklet" which gave basic information; they could then have asked questions from there. They did not really know what the appropriate questions should be but, in retrospect, would have certainly asked about epilepsy.

In general, Carol's parents were philosophical about the present situation. They feel they have to cope. As they put it, they cannot be expected to be "propped up" and must help themselves.

DON

Don was driving his car on a Sunday afternoon. The car went over a bank. There were no passengers or witnesses and the cause of the accident is not known.

Age at time of the accident: eighteen. Occupation: farm hand. Condition on admission to hospital: Unconscious. Multiple skull lacerations. Left ulnar palsy. PTA: four weeks. Categorisation (this sample): "very severe head injury". Has intellectual impairment. Weakness of left arm.

The same person as he was before the injury?

Before his injury, Don was a shy and quiet person. He now becomes frustrated very easily and this leads to anger, although not to aggression. His mother described him as having "a short fuse". He is much more impatient than he used to be. He now has a very low tolerance for alcohol, and his drinking is causing his mother very real concern. He has lost his driver's licence for drunken driving. She considers that he leads a very unpatterned life, for example eating only when hungry and ignoring conventional meal times. There appears to be a general change in his attitude towards life which he now views either negatively or with disinterest. There were major episodes of depression earlier, during which he threatened to hang himself. Don is now very easily led and exploited by others. His mother considers that Don's earlier sense of responsibility has much diminished. He has been involved in episodes with others which led to police enquiries. He has not experienced social isolation but his mother is worried about the "bad types" he now associates with. She considers his judgement about other people is impaired; this also applies to management of his finances. Don's short-term memory is erratic and he has concentration difficulties.

Which changes have been the most distressing for the carer?

Don's mother felt that all the changes in her son since the injury have been distressing at various stages. In the early days following his hospital discharge, she had to treat him like a baby and she wondered if he would ever get better. At present, the most distressing aspect for her is her son's drinking problem which invariably leads to trouble. He has received treatment for this problem and there has been some improvement. She also mentioned that his physical and mental slowness caused her concern.

Possible future changes and particular concerns

Don's mother hopes he will improve further. She sees no reason for a change in the level of help and support presently being received by her. She is prepared to continue in her role of carer, as at present.

The respondent felt that she had no particular concerns about the future as she was sure that other members of the large family will continue to care for Don when she is no longer able to do so.

Leisure activities

Don can no longer play football and is confined to a spectator role. He has resumed tennis. The reason for no longer playing football was given as physical handicap.

There has been no change in the carer's former leisure interests.

Additional expenditure relating to caring for the patient

Extra expenses have related to transport and food.

Carer's confidantes and friends

The informant confides in Don to a limited extent about problems. She has another son with whom she regularly discusses matters of

concern. Her friendships have not altered since Don's injury.

Family roles and relationships

Don is the youngest of a large, grown-up family. He has now become very dependent on his mother again. She resumed the parental role at a time when she had reached retirement status.

Effects on the family unit

Don's mother commented that some of the other children were very emotionally distressed about Don's injury. They continue to be very supportive of him and there has been no real change in the family unit's inter-relationships.

Other comments

Don's mother found the period immediately following Don's injury to be very stressful. She lived some distance away from the hospital but visited him every day for the four weeks he was unconscious. As she put it, "I never knew from one day to the next if he would pull through". The informant felt that professional counselling would really have helped her. This was not offered. As Don lives with his mother, his independence has not really been tested. He tends not to discuss his problems. His mother commented, however, that Don is aware that he has been "one of the lucky ones" in the sense that he is not in a wheelchair.

EVAN

Evan was loading a horse into a truck. The horse became agitated and kicked him in the head.

Age at time of the accident: forty-two. Occupation: self-employed farmer. Condition on admission to hospital: Compound depressed frontal fracture extending into left temporal region. Pulped frontal lobe herniated through wound. CAT scan showed cerebral contusion both frontal lobes, extending into parietal lobe on left. Fractured maxilla. Unconscious, not responding to pain. PTA: eleven months. Categorisation (this sample): "extremely severe head injury". Has severe intellectual impairment. Epilepsy. Severe memory impairment.

The same person as he was before the injury?

Evan's wife described him as being a strong, determined, dependable, private person prior to his injury. He is now more emotional and can become aggressive if "pushed". He is less placid than before. Evan now tends "to do only what he wants to do" and needs reminding about relatively simple daily tasks. His wife considers that Evan uses passive resistance "as a way of asserting his independence and regaining some control over his life". The respondent stated that Evan cannot make decisions or take the same degree of responsibility as before. He is socially restricted and he has lost his former interests. Evan is able to relate well to people he knows but "panics" with those he doesn't; words do not come properly in such situations. Evan's wife thinks he has lost confidence because of his problems with epilepsy.

Which changes have been the most distressing for the carer?

Evan's epileptic seizures cause the respondent great concern. As well, she now has to take the decision-making role and run the farm. All the problems are hers. The children leaned on Evan before his injury; this has now changed to a role reversal.

Possible future changes and particular concerns

His wife hopes that Evan will continue to improve further. There have been gradual changes over the past year or two: "Now there are five good days and two bad ones - previously it was vice versa".

Evan's wife hopes there will not be any reduction in the present level of help and support being received by her. She could not cope without it.

As far as her present caring role is concerned, the respondent does not foresee any real change. She feels that a pattern has now been established and views the situation as "her lot". The only change would be if Evan unexpectedly made great improvement and was able to resume the running of the farm.

Evan's wife wants to push him towards maximum independence - the ultimate goal is that he could live by himself. If anything was to happen to the respondent, she does not want the children to have the responsibility of caring for Evan.

A particular concern centres around the present farming operation. If economic factors were to force a farm sale, the family's present life style would change dramatically and a new set of adjustments would have to be made. The respondent described the present farming operation as being a constant challenge to her, which also had the benefit of involving plenty of people contact.

Leisure activities

Evan's former main interest of show jumping no longer continues. He attends the local Lodge only infrequently now. His other previous interests centred around the farm. Evan's physical handicap was given as the reason for not continuing with his former interests.

The respondent was previously secretary of various organisations. These interests have been given up because they are now "too much hassle". She gave up her previous occupation to care for Evan and to run the farm. Previously, they shared farm tasks.

Additional expenditure relating to caring for the patient

Additional costs had resulted from a contribution towards house alterations, the necessity to purchase additional farm transport for Evan, travel and transport costs, and the need for Evan and his wife to have regular time away from the home situation.

Carer's confidantes and friends

The informant continues to confide fully in Evan about problems. She also has regular confidantes in a friend and the district nurse. Friendships have remained unchanged.

Family roles and relationships

The respondent described Evan as beginning to assert more authority but earlier he was like a dependent child. The childrens' relationships with him have changed. Evan's wife now has all the responsibilities; these were shared with Evan before his injury.

Effects on the marriage

Evan has become much more reliant on his wife. She is head of the household now. Prior to Evan's injury, the marriage was a partnership in all respects.

Effects on the sexual relationship

Evan is now much less interested in sex than he was before the injury. However, the respondent stated that this was not a major problem.

Effects on the family unit

The respondent said that she did not realise until the accident just how close-knit the family was. Although Evan is no longer head of the household, the family unit remains intact.

Other comments

The respondent commented that, in the very early days after the injury, there is a tendency to try and identify one's own case with other cases, that is: "Will he be as bad, worse, or better than that other person". Eventually one realises that each case is individual.

Evan's wife recalls that, very soon after Evan's injury, "professionals" insisted on providing her with "the worst possible scenario". One nursing sister apparently told her that, "Your husband will be in hospital for the rest of his life so go home and get the farm in order". Others talked about prognoses two years' into the future. She felt unable to cope with that projection. Evan's wife considered that head-injured patients were treated badly in hospital, the attitude being "no brain, no pain". At one stage, Evan had a wound stitched without anaesthetic and there was another episode relative to an infected catheter.

Concerning information about head injury, the GP travelled in the ambulance with Evan and his wife immediately following the injury; he provided general information about head injury on the way. However, the respondent commented that she asked for more and specific information about head injury at the Rehabilitation Unit but this was not provided. Evan's wife was not warned of the possibility of epileptic seizures before Evan was discharged home. She was very distressed when the first seizure occurred: she did not know what was happening or how to deal with it. The respondent found the Accident Compensation Rehabilitation Co-ordinator and the local district nurse to be excellent sources of head-injury information. Evan's wife considers that there has

been a need for Evan to receive professional counselling from another male. He has tended to be "surrounded by women". Their son also needed counselling help but this was not offered. His need was related to feelings of guilt about the accident as it was his horse that was being loaded into the truck. The respondent coped without counselling and felt that her own earlier personal experience of injury had added to her coping skills.

Evan's wife has learned "never to let him get away with anything". Once Evan sets his mind on something she needs to "back off and pander". She feels that she might end up with a "bigger problem" if not, as he might "go mad". He has never been "pushed enough to find out". She waits for Evan to calm down and then tells him, "What you did before was not fair". She feels that otherwise he may use these episodes as "weapons". The respondent considers that there is a trap in being overprotective and it is probably necessary to push Evan to the maximum. She does worry about this, though, as he tends to "run out of energy".

Evan's epilepsy is controlled to some extent by medication. However, he tends to have seizures associated with a "stress and panic syndrome". His wife feels that Evan may have had seizures earlier out of boredom; these days it is more likely to happen when he becomes overstimulated. She now evaluates situations such as travelling in terms of "whether or not it is worth it, because he is likely to have a fit that day or the next". The seizures occur quite regularly every three weeks but pressure or overstimulation cause them to occur more frequently.

In many ways, Evan's wife feels she has changed more than he has. She described herself as being aggressive before Evan's injury but she has now learned to "let things happen instead of making them happen". She feels she has become more easy-going in order to cope. It is her view that those who can't change themselves may end up "opting out".

Evan's wife felt that, in some ways, Evan's recent improvement has made it harder for her to cope than in the earlier days. She now needs to: explain everything, not let him "get away with things", "push him to his maximum", and use tactics like offering him a choice of tasks ("would you like to clean the windows or clean the cars?"). However, he can now fill in his days, although he needs to rest twice a day in order to cope. It was an earlier major problem to provide him with interests. There were no day-care or activities centres available in the area. Despite Evan's desire to help on the farm, this is a real problem in itself because tasks rarely get completed because of his slowness. There is also a need to constantly supervise him. The farm has "gone backwards" as a result.

The respondent, in a summing up of her role as carer, described the overall situation as one of "delicate balance" which necessitates "playing it all by ear".

FRANK

Frank fell from scaffolding while inspecting equipment. Initially he appeared to be suffering only from concussion. He later went into a coma.

Age at time of the accident: thirty-four. Occupation: equipment inspector. Condition on admission to hospital: Unconscious. Left temporal extra-dural haemorrhage. Left third nerve cranial palsy. PTA: ten weeks. Categorisation (this sample): "extremely severe head injury". Has mild intellectual impairment. Both legs weak and spastic. Poor balance, uses walking stick.

The same person as he was before the injury?

Before his injury, it took a lot to make Frank angry. He now gets frustrated with his restrictions and "loses his cool" quite easily; the anger is not directed at others, however, but towards himself. He is very conscious of his present limitations and has lost confidence and self esteem. Although Frank has no trouble in communicating with his wife, family, and close friends, he has communication difficulties with other people. He is inclined to "just sit there" without contributing to conversation. He takes much longer now with daily routines and his frustration is evident. Frank's speech sounds different since his tracheostomy. There is a tendency to over-react emotionally. For example, he keeps on laughing much longer than is usual. Frank's wife commented that "the weeping aspect has not really been tested" but she "feels he would go to pieces". Frank has short-term memory difficulties. His wife resorts to writing lists for him but said that he is better at remembering things that are important to him personally. In general, his loss of confidence has affected his attitudes. He is much more self-centred now. He lacks his previous patience.

Which changes have been the most distressing for the carer?

Frank is inclined to take out his own frustrations on himself, rather than others. For example, he will say, "I'm so angry with my stupid leg" and proceed to beat it. It hurts Frank's wife very much to see this. His movements are now very slow. It has become necessary for the respondent to slow herself down to match his pace. This causes tension, especially as she is working and "there is so much to do". She described their life style as having "changed to the pace of a turtle".

Possible future changes and particular concerns

Frank's wife considers that he will be in a wheelchair within five years. He does not have sufficient physical strength to keep going.

The respondent does not foresee any changes in the level of help and support presently being received by her. Nor does she expect her own role as carer to alter. In the longer term, she has no particular concerns as she feels that Frank could live independently if this became necessary.

Leisure activities

Frank has given up his three main former interests of powerboat racing, rugby, and golf. Socialising with friends does not take place any more. Frank's reading ability has become very limited. The reasons given for the changes were those of Frank's physical handicap and loss of former friends.

The respondent has also changed her own interests. These were previously shared with her husband.

Additional expenditure related to caring for the patient

The informant stated that these related to transport and general wear and tear on the car.

Carer's confidantes and friends

Frank's wife continues to confide in him fully about problems. She also has a friend with whom she discusses problems occasionally. Although close friends remain the same, the informant reported that "distant friends have all disappeared". She said that Frank used to help these people before his injury but "they have dropped him because he is no longer useful to them". People have avoided him in the street. Frank's wife "no longer trusts many people". She commented that the children's friends accept Frank without problem but older people appear to have more problem.

Family roles and relationships

There has been a role reversal. Frank's wife now works in paid employment and also carries out most of the tasks formerly done by her husband. He attends to some of the domestic chores. Frank is no longer able to engage in physical activities with his children as he did previously.

Effects on the marriage

Frank's wife is now the dominant partner. The couple have always "talked things out" and this has not changed.

Effects on the sexual relationship

Frank is now unable to carry through the sexual act as before and experiences frustration and anxiety about "performing". The respondent hoped that the present problems may be overcome. She is able to accept the changes.

Effects on the family unit

The lifestyle has altered. Previously the whole family was very outgoing, constantly out and about doing things. Now they tend to stay at home. Before Frank's injury, the family enjoyed beach outings but this interest has been abandoned because of

Frank's present inability to walk on sand.

Other comments

Following Frank's accident, his wife's greatest immediate problem was having the children cared for while she stayed with Frank in a hospital located a considerable distance away. He was hospitalised there for two months, and later transferred to a local hospital. She does not know how she would have coped without her parents' help. There were financial worries. The respondent considers that a parent with very young children would face particular problems, especially without family help. The informant commented that nobody at the hospital ever asked her how she and the children were coping. The concern was all for the patient. There was no contact by a social worker during the time Frank spent in the Intensive Care Unit, the hospital wards, or the Rehabilitation Unit. She had no idea of her ACC entitlements. Frank's wife stated that she is a very independent person and accepts assistance only when it is offered. She thought this may have worked against her.

Following the accident, Frank's wife was told by a neurosurgeon that Frank would probably be "a vegetable"; if not, he would never walk again. She was initially shocked but then told him he "did not know what he was talking about". Frank's wife acknowledged the need for her to be warned in case the prognosis turned out to be accurate. However, she felt that specialists do not take into account the personalities of both the patient and the carer. In this case, both Frank and his wife are "stubborn" people who do not give up easily. Following this, the medical staff failed to keep her informed. Frank's wife made sure she was at Frank's bedside when the doctors' rounds took place. She went to physiotherapy and occupational therapy with him, continually asking questions and learning techniques. Had she not done this, the respondent said she does not know how she would have coped when Frank came home. Frank's wife feels that information should be freely provided as a matter of the family's

right. This needs to include explanations of the patient's current condition and treatment procedures, together with warnings of possible problems. The respondent felt she was fortunate in that she previously knew quite a lot about head injuries. She was satisfied with the quality of the medical care Frank received while in hospital.

The respondent said that an announcement was made to her one day that Frank was being discharged home. Nobody discussed with her whether or not she could cope, whether the house could accommodate Frank's wheelchair, or how she was managing financially. Frank's wife considers that there should have been a session with the doctor and physiotherapist regarding the possibility of epileptic seizures, muscle spasms, and "everything else that could possibly happen". Written material about head injury should also be provided. This would then give the carer some "control over the situation" by way of having information and knowing what to do. When he first came home, the respondent found the physical care of her husband very demanding. She had "to do everything for him, including getting him in and out of the bath, toileting him, and so on".

Although Frank received psychological assessment, there was no "follow up". Psychological counselling was not provided for either the patient or his family.

People sometimes talk to Frank's wife "over his head" as if he was not even present. She has tried to excuse them, but feels she has become a "harder" person as a result.

The respondent commented that, had she known what was going to happen, she would have felt that she could not cope with such a situation. However, she has "got the strength from somewhere" and recognises that "one copes when one has to". One of the hardest parts for her was in answering the children's questions. She felt she needed to be honest to keep their trust. There were times in the earlier days when she thought it might be

better if Frank died. She felt very guilty about this. She was physically affected by the stress, losing two stone in weight. Frank's wife feels that, although there is initial denial, one quite quickly accepts reality. As she said, "It is not possible to delude oneself forever".

The respondent thinks that Frank has received so much attention over the last few years that he has become self-centered. His horizons have narrowed, and there is much less contact with others. Frank's wife also considers that society is prejudiced about disability: he would like to work but his movements are too slow for him to be acceptable to an employer.

Overall, Frank's wife felt that it was all the "little things" that are the problem. For example, they can't go to the beach, go anywhere involving stairs (cinema and restaurants), and can't dance. The patterns of their previous life have been disrupted. Activities which seem "too much hassle" are avoided. The children's lives, as well as their parents', have been "turned upside down". The respondent said that Frank himself realises that he has been relatively lucky and "can't go around feeling sorry for himself". The respondent felt that his acceptance by his wife and family has helped Frank to adjust to his present situation.

GRAHAM

Graham was driving a van and trailer on a Sunday morning. The trailer whiplashed and the van went out of control. It tipped over and rolled.

Age at time of the accident: twenty-two. Occupation: white water rafting guide (previously University student). Condition on admission to hospital: Unconscious. Fractured mandible. Uncontrolled hypertension initially. PTA: three to four weeks. Categorisation (this sample): "severe head injury". Has intellectual impairment. Dysarthria. Right leg and arm weakness.

The same person as he was before the injury?

His parents felt that Graham was basically the same person. However, his future is uncertain and unsettled, especially occupationally. He seems unable to find his "niche". His self-esteem has been affected. He now "finds life a trial, and he is not comfortable with himself". If he gets emotionally upset, there tends to be some speech hesitancy. His parents consider that Graham's emotional reactions relate to his loss of self-worth. People who know little about head injuries seem to think Graham "is not all there". Prior to his injury, Graham pursued physical activities. He now "ponders" more and writes poetry. His father felt that Graham does not have the same "personal finesse" as he did before his injury.

Which changes have been the most distressing for the carer/s?

It causes Graham's parents distress to see him so unhappy. He appears to lack peace within himself. His occupational goals may be unrealistic and they feel that he needs to accept that it is possible to be happy even with a "menial job".

Possible future changes and particular concerns

Graham's parents expect him to improve even more. He "just

needs to become more settled".

As Graham lives independently, no change was anticipated relative to the level of help and support needed by his parents. They did not foresee any changes in their role of carers.

Particular concerns centred around "if doors keep closing and he does not achieve spiritual peace, he may become severely depressed". His parents felt that it is hard for Graham to maintain his confidence.

Leisure activities

Graham has given up his two major interests of hang gliding and competitive canoeing. This has been because of his physical handicap.

The carers have not needed to change their leisure interests.

Additional expenditure relating to caring for the patient

This has related to helping Graham with finances. He is only just learning to cope with money himself.

Carers' confidantes and friends

Graham's parents still confide in him fully about problems. They have each other for support and discussion when needed. There has been no loss of friendships. Additional friends have been made through the head injury support group.

Family roles and relationships

There has been no real change.

Effects on the family unit

The family has always been a close one and this has not changed. "Everyone is just getting on with their own lives".

Other comments

Graham's parents felt that day-to-day information about his progress was very good while he was in the Intensive Care Unit. Once he was discharged into a general ward, however, the doctors appeared to know nothing about head injuries. Information was "virtually non-existent". Initially, Graham's parents wanted only to know if he would live, but past that point much more information was needed. They felt that if they had understood the patterns of head injury, they could have helped their son more. As they said, it is very beneficial to carers "to do positive things". Graham's parents commented that, when the head-injured person is an adult, some types of information (for example, psychological assessment) are "kept secret" from parents for reasons of patient confidentiality. They considered that psychological counselling was insufficient, being provided to Graham only once because the person concerned was "too busy".

The respondents feel that they "know their way around the systems" but this is not necessarily the case with others. For example, they were critical of the Accident Compensation Corporation who they described as having "no idea of what was happening and couldn't care less; all the Corporation wanted was medical certificates or the result would be that (Graham's) weekly benefit would stop". The family lived in a large house at the time Graham was discharged home from hospital. Nobody offered any home help although this was really needed.

Graham has retained his independent spirit throughout. He went off to live on his own about a year after the accident. Graham's friends thought the parents were over-protective and encouraged him to leave home and move to another part of the country. Graham's parents thought this may have been "a good thing" but he had not completed his programme at the Rehabilitation Unit at the time. Graham's friends were very supportive of him. This was particularly necessary because of his memory problems. In the earlier days, Graham tended to get

very "uptight" and angry. When he was upset, he "turned things around and made out it was the other person's fault". His relationship with his girlfriend ended. It was difficult for the other children in the family to accept Graham's moods and attitudes and they were frequently hurt. Graham has tried to change and there has been improvement recently. His expectation has been that he would make a complete recovery from his injury and he has difficulty in accepting that this is not the case.

Graham had completed first-year University studies prior to the injury. He was in employment at the time of the accident. He attempted to return to University following the injury but could not cope with study or exams because of concentration problems. He felt a failure. Graham's parents thought that his cognitive function may have been helped to some extent, however.

Graham has worked spasmodically at casual labouring jobs. In one of these jobs he became very depressed. He seems unable to accept tedious, repetitive work. Graham would like to help others. His injury has given him empathy with "down and outers".

Graham's parents feel that head-injured people need a special confidante in whom they can confide. Parent/child or husband/wife relationships do not meet this need. They feel that a "buddy system" through local head injury support groups would be a very good idea.

HARRY

Harry was playing Polo. The horse stumbled, the rider was thrown, and the horse fell on top of him

Age at time of the accident: thirty-five. Occupation: self-employed farmer. Condition on admission to hospital: Deeply unconscious. Required artificial ventilation. No fractures or haematomas. Cerebral anoxia. PTA: six weeks. Categorisation (present sample): "very severe head injury". Has mild intellectual impairment. Spastic tetraplegia. Severe dysarthria.

The same person as he was before the injury?

Harry's wife said that there have been a lot of personality and behavioural changes but that glimpses of "the old character" were apparent from quite soon after the injury. Before the accident, Harry was a "stropky" person who wouldn't stand any nonsense from others. Now his anger stems from the frustration of his own limitations and his current situation. Harry is confined to a wheelchair because of spastic tetraplegia and needs constant care and supervision. His speech has been affected and it now requires great effort on his part to project his voice so that others can hear him; he needs to be motivated to do this. He has good cognitive function. Harry now lives in an institutional setting but his wife continues to have overall responsibility for him.

Which changes have been the most distressing for the carer?

Harry's wife regrets the loss of his sense of humour. Prior to the injury, he was "always laughing and acting the fool" but has no humour now. He was also a talkative person but now there is an overall lack of response to others. The respondent commented that he "seems untouched by what is going on in the world". His previous "sparkle" has been lost. Harry was a very fit, active and physical person before the injury. He now looks, sounds,

smells and dresses like a different person. Harry's wife felt that the intellectual and personality changes are worse than the physical changes. She feels that she could have handled her husband becoming a paraplegic.

Possible future changes and particular concerns

Harry is becoming increasingly separate from his wife and child and adjusting to life in different surroundings. The respondent considers that he "will begin to lose contact with his old life, and his new life will take over; this will mean less internal conflict over what has been".

Regarding help and support, Harry's wife commented that "one gets to the point where one needs to become very self-reliant". She sees her own role of carer changing. She was determined from the start that Harry would be as independent as possible. Now that they are no longer living together, she feels that the caring role will lessen, especially as Harry's mother has resumed a parental role. But Harry's wife wants "to see it through until his transition to a new life is made".

Particular concerns relate to long term provision of care. If the present institutional arrangement alters, "the ball would be back in (the respondent's) court". There may also be physical problems later, although Harry is very well at present. The informant is also concerned that Harry might shift his allegiance totally to his mother, who is now quite elderly but has resumed a parental nurturing role.

Leisure activities

Harry played golf and polo before his injury. He also worked long hours on the farm. His interests are now more passive because of his physical disability.

The respondent no longer rides horses because she became frightened of them following Harry's accident. Her former

country interests of farming, gardening, and overall life-style were lost totally after the farm was sold. She has retained an interest in reading and sewing and is conscious of the need to pursue other interests.

Additional expenditure relating to caring for the patient

Prior to Harry's move to an institution, live-in carers meant "extra mouths to feed". There were "enormous" laundry expenses because of Harry's then incontinence. His wheelchair caused damage in the house. There was a constant need to purchase items to entertain Harry and give him things to do. Transport and travelling expenses were also high, and only partially reclaimable from the Accident Compensation Corporation.

Carer's confidantes and friends

The informant confides in Harry to a limited extent about problems. She has a relative who is an occasional confidante. Harry's wife stated that "friendships have changed totally and social networks have disintegrated". She has retained many of her pre-marriage friendships, however. There has been some "taking of sides" by former friends of Harry. Some people who were previously acquaintances have developed into friends.

Family roles and relationships

The respondent's role changed from that "of a wife and mother to that of breadwinner, organiser, nurse, advocate, and business manager". Harry's role changed from provider to dependant. Their child is conscious that there is a difference between herself and other children; her mother is virtually a solo parent. There is an element of "two-way affection" missing in the relationship between father and child.

Effects on the marriage

The respondent stated that Harry's injury has totally destroyed their marriage. However, she has never considered Harry to be

other than her husband and interacts with him as such. She felt that "there is no-one else to fill that special role".

Effects on the sexual relationship

This was never resumed after Harry's injury because of his physical disability.

Effects on the family unit

The family unit has been split. They do very little together as a family. When this is tried it is frequently a disaster. The respondent can manage her husband or young child separately but "both together is very difficult".

Other comments

The respondent received very good information from Intensive Care Unit staff following Harry's injury. Once he was transferred into a general ward, however, the staff appeared to know very little about head injury and the informant said that Harry was left alone for long periods. He was given a bell to ring but simply chewed through it. Harry's wife found the physical manifestations of his injury very frightening. She needed information and support but this was not received. There had been earlier conflicting medical opinion. One specialist told her that "there will be a good recovery but it may take a long time"; the respondent thought that Harry would be helping on the farm within two years and would later resume management of the property. Not until six months after the injury did "reality become apparent". At first, Harry's wife thought his physical problems were the major ones. She did not appreciate until later that the behavioural aspects were much worse. She felt that she did not get enough information about what to expect. Information tended to be given "after the event".

The respondent felt that she was treated in the same way as parents of a head-injured person. However, she felt that they

have each other for support whereas a spouse may be very much alone. Harry's wife considers that more head-injury information and education is required. Head injury support groups can also play a part with network support. She considers that basic information should be supplied by the hospital, supplemented by written material, videos, and contact with appropriate people who have had first-hand experience of head injuries. She feels there is a need for a booklet explaining "what might happen, and what to do about it if it does". Harry's wife mentioned that relationship information, including the sexuality aspects, were never discussed with her. She gained information from reading magazine articles, autobiographical accounts, and other written material.

The respondent had an earlier need for psychological counselling. She described herself as being "very fragile and not wanting a disabled husband". There was no psychologist available but, after "pushing for weeks" she eventually received the requested assistance. She found it to be of no help, and there was no follow up. Harry's wife feels that counselling assistance was needed not only for herself, but also for Harry's parents. In her case, there was "high in-law involvement and interference" which caused inter-personal difficulties. She considers that if various issues had been clarified at the beginning, many of the present problems would either not exist or not be as bad. In his wife's opinion, Harry also needed counselling but received only psychological assessments.

The respondent found the family GP to be unsupportive. Although he had received hospital notes, he seemed disinterested. She later changed to another GP who provided an excellent level of interest, concern and support.

Harry required attendant care when he was discharged home. His wife had "endless problems" with carers provided through an agency. They had no training in disability and some found Harry to be "threatening". He was not good company. There was also a

requirement to lift Harry who is a heavy man; the respondent had to train the carers in this regard. In general, the carers stayed a very short time and there were thirty to forty carers over a period of 2.5 years. The respondent described that time as "a nightmare". For financial reasons she took up paid employment. When she returned from work she would not know if the carer would still be there, or was planning to return the following day. The respondent commented that agencies must prepare attendant carers for what to expect: the more stressful the situation, the more the staff need appropriate personal skills. The agency appeared never to bother to "check out the situation" or provide Harry or his wife with choices. They simply sent people to the house, expecting the respondent to "take what is available". A later change to another agency produced better selection and a carer who remained for a relatively long time.

Harry's wife commented that an activities centre is needed for head injured people where they can participate in social activities. For example, ten-pin bowling, meals and so on. Many are socially isolated.

The respondent also felt that relief care was required regularly where there was a situation of the head-injured person needing constant care. She considered that a full weekend off per month was needed.

Another concern mentioned by Harry's wife was that of ongoing physiotherapy treatment. There tended to be no overseeing of home exercise programmes and the whole area was one of "hit and miss".

Following a decision to sell the farm, mainly for financial reasons, Harry moved to his present living arrangement. He has been there over a year now. There were initial problems with his angry moods but these resolved. The respondent feels relief

that her day-to-day responsibility has gone. She has a full-time occupation and, after a busy day, has difficulty enough in coping with her child. She could not cope with Harry as well. Their child now has a focus that was missing in earlier days.

The respondent said that she felt totally defeated when Harry went into the institution; she felt that the whole situation had "beaten her". She later realised that "enormous fatigue was not laziness". Harry's wife considers that "women are conditioned to be nurturing, and accepting of self-sacrifice or martyrdom". She does not believe that a woman should be expected to give up all her own needs and ambitions for the rest of her life. Harry's wife feels that her job kept her sane. Now that the caring role has been abdicated, she has been "released from the nurturing bind". She still has a child to care for and finds it difficult to leave the child in the care of others while she is at work. The respondent also finds it hard to have only one child as she and Harry had planned to have a larger family. The respondent sees Harry only at weekends now or if there are special events. She feels detached from his life.

IAN

Ian was knocked off his bicycle by a car. He landed on his head. He was not wearing a bicycle helmet.

Age at time of the accident: twelve. Occupation: school student. Condition on admission to hospital: Unconscious. No reactions. PTA: unable to be assessed because patient cannot communicate adequately. He was unconscious for six months. Categorisation (this sample): "extremely severe head injury". Severe intellectual impairment. Tetraplegia. No speech.

The same person as he was before the injury?

Ian is very severely disabled. He suffers from spastic tetraplegia and can do nothing for himself. He was a very articulate person before the injury and now cannot speak. He is able only to shake or nod his head. He cannot chew or swallow. He is incontinent and permanently catheterised. Ian is unable to read or carry out even simple tasks. Despite his severe disability, Ian's mother said that he has retained his sense of humour. He was a shy and introspective person before his injury, relating better to his parents than his peers. The company of others has now become very important to him. There are no real patterns of mood changes and "he is constant day to day". The respondent commented that Ian had a very sunny nature before his injury and seems to be "even sunnier now". His mother considers that the "essence" of the person is the same. Comparisons are fading as acceptance grows of the person he now is.

Which changes have been the most distressing for the carer?

Ian's mother felt that the totality of his disability was the most distressing aspect. As she said, if he had lost a single limb he would still have the use of the rest of his body. His lack of speech is another major area of distress. Particularly as he grows, his mother is aware of all he is missing out on as a

youth. The loneliness of his life appals her: she described him as "a social outcast". From a mother's viewpoint, she considers that "this should not have happened to (her) child".

Possible future changes and particular concerns

The respondent does not hope for "a miracle cure" for Ian. She feels that if even a small improvement occurred, this would constitute a miracle in itself. She prefers to be realistic. Ian's mother said he knows that he is "loved and wanted" and is never considered to be a burden. They could not imagine life without him. His parents relate to him as they always have, rather than to a person with a disability.

Of particular concern to Ian's mother is that something may happen to her husband and then life would become doubly hard for her. She would then need alternative sources of help and support. However, she has learned not to look too far into the future.

Leisure activities

Ian used to read a great deal and type stories. He also enjoyed Leggo construction. His interests were mainly cerebral and he was not interested in sport. His severe disability precludes these former interests. His present main interests centre around television and the family cat.

Ian's mother used to write and read. Apart from caring for Ian, all her spare time is now taken up with a head injury prevention project. She gave up her former occupation to care for Ian.

Additional expenditure relating to caring for the patient

Ian's parents met part of the cost of house alterations following Ian's injury. They are currently saving towards the purchase of suitable transport to accommodate Ian and his wheelchair.

Carer's confidantes and friends

Ian's parents are unable to confide in him about problems. They have each other for confidantes and support whenever the need arises. Close friends have remained the same and distant friends have increased. Ian's mother commented that she is "a private and independent person". However, in the time immediately following Ian's injury, she really needed "hugs and comfort" but most people confined themselves to asking questions about Ian's progress.

Family roles and relationships

Before his injury, Ian was old enough to care for himself. Now his parents are "24-hour nurses". The parents are no longer able to "do their own things". However, they "were not stereotyped people" before Ian's injury and this has helped.

Effects on the family unit

The respondent considered that Ian's injury has strengthened a previously good marriage. Any changes within the family unit have been positive ones. His mother said that Ian is aware that the three-way relationships between his parents and himself are still strong.

Other comments

Ian was not expected to live after his injury. For the first month, his parents prepared themselves for his death. His mother felt that Ian's excellent physical condition at the time of the accident enabled him to survive, despite several critical episodes. The parents then needed to adjust to what they were told would be Ian's "vegetative" state. His mother said that she never expected Ian to return home. She was sure she would be "visiting him in an institution". There were times when she wished he were dead.

The respondent described Ian's move from the Intensive Care Unit

to a general ward as an extremely traumatic time. There was a "dramatic change" from the security and constant attention of ICU to a situation where "he was overlooked because he was easy to ignore". His mother was very unhappy with the standard of nursing care. Her anxiety resulted in angry confrontations with the medical and nursing staff. She felt they became afraid of her.

Ian's parents received fundamental information about head injury from ICU staff. However, they were not warned about "what to expect". When Ian recovered consciousness after six months and opened his eyes, his mother expected "communication would then start". Written material at that time would have been very useful to her and helped to answer the "whys". She has subsequently obtained head injury information from her own sources. In the general ward, doctors tended to make comments such as "every case is different", "don't know", or focus on the respondent's day to day complaints about Ian's treatment. The respondent commented that "doctors arrive in a swirl of white coats and have no time to talk". She felt that "doctors expect you to genuflect and are horrified when tackled; they expect swooning at the sight of a white coat and swinging stethoscope". However, the respondent considered that the Rehabilitation Unit doctors were better: they were prepared to talk and listen "on an equal footing". She was less happy with physiotherapists whom she described as having "dumped" Ian "because he was difficult".

The respondent was critical of the Accident Compensation Corporation. She felt that "their opinion is that he is so badly disabled they don't want to throw their money away because he will never be rehabilitated". Ian's mother described having eventually received all the special equipment she requested for Ian but "only after a constant fight". The respondent commented that some of the ACC staff "should have to take care of Ian for a week". She felt that the Corporation could have made her life easier and she felt demeaned by "having to claw aggressively for

every dollar" when she considered that there was every right to such assistance. Ian's mother commented that, despite the "huge sums" involved, it would have cost much more to keep Ian in an institution. She feels that Corporation staff "lump all people together" and are "so used to dealing with the downtrodden or those ripping off the system that they can't distinguish any more". The respondent felt that Corporation staff treat her more deferentially now because they are afraid of her.

Ian's mother feels that there is a need for a centre specifically for head-injured people. She commented that "disabled people are not all the same, even though they may appear the same from the outside". She felt that the rage and personal grief of the injured is not taken into account. Her opinion is that the expectation of staff at centres like the Crippled Children Society is that Ian "should be a nice, well-behaved disabled person instead of a bloody nuisance when he gets frustrated and screams". The respondent considers that Ian resents being "patronised" or "treated as something less than human". Ian's mother felt that, because Ian cannot speak, he "is often viewed by others (including the "professionals") as mentally retarded or lacking in intelligence; they tend to ignore him or treat him like a half-wit". This makes Ian's mother very angry. She has always been angry when Ian is treated with what she perceives as "less than dignity".

The respondent considered that Ian feels totally secure in his home environment but there are some drawbacks to this as he does not like leaving home. In places like the Rehabilitation Unit he gets angry and frustrated if left alone for long periods.

The respondent found it very hard to contain anger, especially in the first year following Ian's accident. Although there were times before Ian's accident when she became angry, she felt that the difference this time was that she "was stuck in the situation". She cannot see herself as "a Pollyanna". She considers that the energy that she put into "fighting" medical

staff and the ACC helped to dissipate some of the anger. The respondent recognised that she was "railing against fate" and did not really "like" herself. She felt isolated and lonely because of her anger and thinks she "gave off an angry aura" which kept other people at a distance. At times, she felt as if she was "falling through a black hole". However, she thinks that it was all part of the grieving cycle and she eventually reached acceptance in her own way. Ian's mother's strong commitment to a head injury prevention project also helped her to "stay sane".

Ian's parents have not yet felt a need for relief care, although they are aware it is available.

JOHN

John was driving a car in the early hours of the morning. He hit a power pole. There were no witnesses and he was not found until two hours later. Some alcohol had been consumed before the accident. There was also speculation that John may have experienced a minor epileptic seizure.

Age at time of the accident: twenty-five. Occupation: factory worker. Condition on admission to hospital: Unconscious. Left hemiplegia. PTA: three days. Categorisation (this sample): "severe head injury". Mild intellectual impairment. Dysphonia. Left hemiplegia.

The same person as he was before the injury?

His mother felt that John is a much less volatile person than he was before the injury. He is easier to talk to and listens better. This has brought the whole family closer. John was not an easy person to live with prior to the accident. He had suffered a stroke as a young child and some degree of brain damage appears to have occurred at that time.

Which changes have been the most distressing for the carer?

John's mother considered that her son's loss of mobility and his propensity to choking fits have been the most distressing outcomes of John's injury. He also suffers a lot of pain.

Possible future changes and particular concerns

The respondent thinks that John will lose his present independence and have to return home to live. He is less well than previously and is slowly losing motor control. Should this happen, John's mother will need increased levels of help and support. She may also have to give up her present occupation to care for him.

Particular concerns relate to John's "going backwards" and becoming more dependent on others.

Leisure activities

John enjoyed wrestling, rugby, tennis and softball before his accident. He can now play only indoor bowls. These restrictions are because of his physical handicap.

The respondent has retained her own leisure interests.

Additional expenditure relating to caring for the patient

Extra costs were involved in travelling and transport. It was also necessary to purchase special food for John.

Carer's confidantes and friends

The informant is able to confide fully in her son about problems. She occasionally has other family members as confidantes but felt that she "could have done with more of this". Both close and distant friends have decreased in number and there is less overall contact. The respondent stated that she is "a private person who tends to survive and cope alone anyway". She was hurt, however, that only two members of the large family into which she was born have provided full support.

Family roles and relationships

John was separated from his wife at the time of the accident. They are now divorced. The respondent considered that John's injury was "the last push" which finally ended the marriage. There are children of the marriage and John is experiencing problems relative to access to the children. In this regard, he needs a lot of personal support.

Effects on the family unit

The respondent felt that the trauma of John's injury "pulled the

family together". There was "a lot of soul-searching". He had been a very temperamental person before the injury and the family realised, after learning more about brain damage, that they were better able to understand his earlier behaviour.

Other comments

John's mother was very satisfied with the level of head injury information provided by the Intensive Care Unit doctor, and also the specialist. She said that they answered all questions and kept John's parents informed of his progress. The respondent commented that this was in marked contrast to lack of information when John had experienced his stroke. She wishes that more had been known at that time as there is a need to understand why a brain injured person behaves as he does. There was also an earlier lack of awareness that John was suffering minor epileptic seizures.

Concerning the ICU, the respondent felt that more than one bed was needed when family members stayed with the patient. She commented that parents need each other for support and are usually too anxious to wait at home.

John's mother said that she and the family felt a need for psychological counselling following John's injury. This was not received. She commented that the assistance was not required immediately following the injury as this would have been "an overload" but it was really needed later. The family felt constantly "burdened" following John's injury and they "seemed to reel from one thing to another". There were all sorts of problems, including financial ones. She said that, to begin with, all focus is on the patient. About eighteen months later, she began "to draw breath and count the emotional and financial costs". There was virtually delayed shock. Relative to the counselling need, the respondent said that the family needed this collectively and individually; some had greater need than others. She felt that other children in the family, especially

teenagers, can become very distressed: they tend to "have a special awareness of life and death issues". Younger children may also become jealous of the constant attention given to the head-injured person.

John went to live on his own twelve months after the accident. His mother felt that head-injured people must be given the opportunity to have independence and lead their own lives. She said that this is a very hard thing to do. The respondent felt that John would have left his parents' home eventually in any case, but it would have been more difficult and perhaps not have occurred on such friendly terms. John had been very independent before his accident. Following the injury, his mother encouraged him to continue to make his own decisions and be independent.

KEN

Ken was a pedestrian hit by a car. The driver was later convicted of being drunk in charge. There were no witnesses to the accident. Ken had consumed some alcohol before the accident.

Age at time of the accident: forty-five. Occupation: head storeman. Condition on admission to hospital: Deeply unconscious. No response to painful stimuli. Fractured basal skull. Large intracerebral haematoma in right central region removed by surgery. Ruptured spleen removed. Hypotensive episode prior to surgery. PTA: four weeks. Categorisation (this sample): "very severe head injury". Mild to moderate intellectual impairment. Left hemiplegia. Poor balance. Mainly confined to wheelchair. Sight affected. Dysphasia.

The same person as he was before the injury?

The respondent described Ken as not being the happy, laughing person he was before his injury. He is no longer as outgoing with people, nor as fond of animals. Ken had excellent manners before his injury but he is now inclined to be bad mannered and much more intolerant. He is confined to a wheelchair.

Which changes have been the most distressing for the carer?

Ken's carer said that his physical disability does not worry her at all. For example, she is never embarrassed about taking him out in a wheelchair. However, she is "ashamed and annoyed about his bad manners". The hardest change for her to accept has been "the loss of in-depth conversation and communication". Ken tends to "forget the content and context of conversation".

Possible future changes and particular concerns

Ken's carer feels that "he is likely to become more withdrawn and morose if the present course continues". It seems that his

moods are influenced by the people he is with.

If Ken's condition deteriorates, his carer feels she will need a lot more help and support. As far as her own caring role is concerned, she stated that the time is limited according to her health, age, and capabilities.

The respondent's main concern about the future is that Ken could be cared for on a "needs only" basis, not having his interests and personal needs met. She considers that this is "the difference between existing and fully living".

Leisure activities

Prior to his injury, Ken's interests were totally focused on sport: cricket, bowls, jogging and soccer. At present he plays only indoor bowls. His restrictions are because of his physical handicap.

The respondent used to play tennis and badminton. She also went swimming and dancing regularly. These interests have all been given up because of Ken's emotional and behavioural state.

Additional expenditure relating to caring for the patient

Extra costs have related to: power (especially heating), a special bed, transport and travelling, and a large number of impulsive toll calls made by Ken.

Carer's confidantes and friends

The informant has learned to avoid confiding in Ken about problems because "he can become like a dog with a bone and keeps referring to the problem over and over again". She has an occasional confidante who is a relative. Both close and distant friends have decreased. This is partly due to a geographical change from one part of the country to another. The respondent finds that people here are more conservative and there has been a

change of focus "from cosmopolitan to blinkered".

Family roles and relationships

Ken was seldom at home before his injury. The respondent and Ken were flatmates. Ken cut the lawns and helped with household tasks. Now the respondent "does it all and nothing is on a shared basis any more". The respondent feels that their relationship has suffered from a loss of communication and from her "carrying all the burdens".

Effects on the family unit

Ken and his carer are companions. Both are divorced and each has a family. Ken now has less contact with his son but the previous intermittent contact he had with other family members remains the same. The respondent's family's attitude appears to be that she is "cluttered" by Ken. Her children feel that she "is wasting her life away". The respondent said that she is not unhappy although she "gets cross at times". She feels that she "is doing something worthwhile". There are "still good times and no opportunity to be lonely".

Other comments

The respondent felt initial resentment about the accident being caused by a drunken driver. Since then, she has felt that all her energies have been needed to help Ken. Had he not been very fit at the time of his injury, he would probably have died.

The respondent mentioned that Ken was "virtually forced out of the Rehabilitation Unit". She found this very stressful because there was no time to think through options and make choices. There were problems in finding suitable housing at short notice and conflict with the Accident Compensation Corporation over housing alterations.

Ken has private physiotherapy. The respondent was very

disappointed about the lack of this treatment at the Rehabilitation Unit.

Ken's carer considers that the Accident Compensation Corporation views her "as an unpaid voluntary worker" and that they take her for granted. She pointed out that her caring role is unpaid and that Ken is not her husband. She "feels tied, just like he is". The respondent is in paid employment. Attendant care is provided by ACC on the basis of fourteen hours per week-day week. Although the respondent considers that more attendant care is required, she prefers to carry out the extra assistance herself so that she can have more privacy.

The respondent organises relief care herself. She is resentful about this. She feels that it should be the responsibility of "one of the agencies" and that she "should just be able to phone and say she wants a day or evening off". Although the respondent has relief care three or four times a year (for a week or less), she has found it harder recently to return home after a weekend away. This seems to have coincided with Ken being more aggressive and abrupt over the past six months. The informant is very pleased with the standard of the relief care.

Ken's carer commented that there have been some very difficult times and that these "have been a real learning experience which others can't understand unless they have lived with it". The respondent has learned that, in order to get co-operation from Ken, she "needs to push the right button, ask quietly and slowly, and not talk down". When Ken becomes frustrated, "anger comes very quickly because he flies off the handle when thwarted". She needs to talk to Ken quietly, and keep calm, "no matter how much provocation". However, she is no longer "jumping to his every whim or babying him". She feels he has to try and amuse himself.

The respondent commented that "there is nowhere for the head-injured to live, except with their families or in a geriatric

ward". She felt that other disabled people like paraplegics and tetraplegics are better off in this regard.

Ken's carer said that he worries about the future. She has found it necessary to make Ken aware that "he will not have (her) forever".

CHAPTER 7

DISCUSSION OF RESULTS

The primary aim of the present study was to establish common themes and patterns relating to: (a) the "world" of carers of head-injured persons, (b) the carers' major areas of stress, and (c) carers' support needs. Secondary aims were to examine the findings in the context of previous research, and to provide information for practical application by others.

This chapter will examine the findings of the present research in terms of the main themes and patterns drawn from respondents' experiences, although atypical examples will be presented as well to provide a balance. Previous relevant research will be discussed as it relates to the findings. The discussion will focus first on specific areas and then proceed to more general discussion.

Theoretical and practical implications from the present research will be discussed in the following chapter, together with the methodological limitations of the present study.

All of the patient subjects had experienced both physical problems and a variety of cognitive/emotional/behavioural/social problems in the year prior to the interviews (refer Appendix D, Table 4). However, when the respondents were asked to comment about their perception of changes in the patients, references to physical changes were relatively few in contrast to the reports made of temperament, behavioural and social changes. Similarly, when asked about the patient changes which caused them the most distress, the respondents reported non-physical changes more than twice as frequently as physical changes (refer Chapter 6, Section 2). This outcome parallels the findings of a number of other researchers that relatives' reports of patients' cognitive, behavioural, emotional, and social changes greatly

outnumber reports of broadly physical changes. These non-physical changes constitute the greatest distress to relatives, particularly the behavioural and emotional deficits (e.g. Brooks et al, 1987a).

It should be noted, however, that two respondents reported positive changes in the patient. This finding is in keeping with the literature which records that there can be a change for the better in a small number of head injury cases (e.g. Vogenthaler, 1987a). Other carers reported that some of the patients had retained former pleasant traits, or that these had become more pronounced. The qualitative nature of the present research may have permitted greater expression of positive comments than is usually reported in other related studies.

In the present study, communication and conversation problems headed the list of mean-ranked patient changes (refer Appendix D, Table 4.3). Similarly, speech, conversation, and interactional problems were reported most frequently in the category of "the most distressing changes", along with patients' social restrictions and isolation (refer Chapter 6, Section 2). This finding is quite different to that obtained in a five-year outcome study by Brooks et al (1986), where communication and conversation problems did not feature at all in the list of the ten most frequently reported problems by relatives. Similarly, Thomsen (1974) reported that the relatives in her study tended to dismiss the patients' impaired language function as a problem although they complained of other changes in the patient. The present findings can thus be viewed as surprising. However, over half of the patient sample had communication problems in the form of: dysarthria (2), dysphonia (2), dysphasia (1), and total loss of speech (1). Respondents' comments indicated that these communication difficulties were linked to the other reported distressing problem of patients' social restrictions and isolation, and/or that communication problems caused frustration to the patient (and sometimes the carer). It is interesting to

note that Thomsen (1974) found that, although almost half of the head-injured patients in her sample suffered from aphasia, only a few attributed their social isolation directly to their speech problems. Patients' social isolation is reported frequently in the literature (e.g. Oddy, 1984). In the present study, patient changes other than those of communication and social isolation were reported as well, of course. Unlike the Glasgow studies, the respondents were not asked to rank the most distressing changes. Changes causing the most distress, then, have been identified in terms of reported frequency rather than rank ordering.

Practical support needs such as home help, attendant care, and relief care appeared to be met in the main. Similarly, special equipment and housing alterations had been sufficient for needs. One respondent had experienced problems relative to child care immediately following the injury and another had found an earlier attendant care agency unsatisfactory. For those living in rural areas, facilities such as day-care or activities centres were not available. Keeping the patient occupied, especially in earlier days, had been a problem. Rural living also meant more travelling. Some respondents felt that there was a need for centres which cater specifically for head-injured persons' activities and social needs. Social isolation was a problem for many patients. These overall findings suggest that carers' present needs for basic practical assistance are met, in the main, with the exception of appropriate activities centres.

The Accident Compensation Corporation, although the funder of most of the practical needs, was viewed unfavourably by more than a third of the carers. Four respondents complained of bureaucratic procedures, uncaring or unhelpful attitudes, and lack of information about entitlements. Three other respondents, however, rated the Corporation favourably and one had found an ACC Rehabilitation Co-ordinator to be a valuable source of head injury information. There may well have been objective justification for some of the respondents' criticism.

However, their dissatisfaction can also be viewed from other perspectives. For example, anger is one of the manifestations of the carer's grieving cycle. One of the respondents had recognised that confrontations with the Corporation and medical personnel had helped her to dissipate some of her anger. Interactions between the carers and other agencies such as the ACC can also be viewed in terms of the transactional analysis model. Karpman (1968) has described "The Drama Triangle" in which "the protagonist" starts off in one of three main roles (Rescuer, Persecutor, or Victim). The "antagonist" is in one of the other roles. In a situation of crisis, these two players move around the triangle and switch roles. Relative to the present study, ACC may be seen initially as the "Rescuer", with the carer as the "Victim". Role switches may occur later, with either the Corporation or the carer becoming the "Persecutor" (i.e. offensive role), and the other the "Victim" (i.e. defensive role). The transactional analysis model, while relatively simplistic, has provided some insight into the dynamics of families with an alcoholic member (Steiner, 1969).

The carers' personal support needs in terms of confidantes appeared to be met in the majority of cases. Most of the carers had relatives or friends in whom they could confide as needed, although two respondents lacked regular or satisfactory access to such confidantes. These were the same two who reported a decrease in both close and distant friendships. Their subjective ratings of overall distress, however, were both below the total sample mean. Other research has found that the presence or absence of confidantes is insignificant as a predictor of relatives' burden (Brooks et al, 1987a).

The comparatively recently-formed head-injury support group was described as an important source of support, information and social contact for a number of respondents. There was expressed regret that it had not been in operation during the carers' earlier stressful periods.

More than a third of the sample reported stress-related problems that had required them to see their GP. As with the absence of friends and confidantes, there was no obvious inter-relationship with their reported ratings of distress. Given the inherently stressful nature of the caring role, it is not surprising that a relatively high incidence of these carers' stress-related problems was reported. Previous research has produced similar findings (e.g. Livingston, 1986).

Carers' complaints of lack of personal support tended to centre around agencies and professionals. Ratings of the quality of the help and support that had been provided varied, according to the individual respondent's experiences, but there were some common themes which will be commented on below. Findings suggest that help and support may indeed have been lacking in some instances, but also that some of the carers may have targeted part of their early frustration and anger towards these same professionals and agencies. Steinhauer et al (1980) comment that doctors are frequently the undeserving objects of hostility by family members. They consider that this is a displacement of relatives' resentment that the event (illness or injury) has occurred, and a reaction against the one who has to confront them with painful realities. Some relatives may actually need a chance to ventilate their emotional reactions before they will be able to listen, co-operate, and make adjustments. Relatives' unresolved resentment may also take the form of bitterness towards family, friends, the community at large, or the patient.

Relative to their experiences with professionals and agencies, the respondents' three major areas of expressed dissatisfaction related to lack of head injury information, lack of psychological counselling for both patient and family, and negative perceptions of head injury specialists. The restricted availability and/or quality of physiotherapy also caused concern to some respondents.

The complaints about the specialists were linked to informational

and support needs - that is, the respondents perceived either that the specialist had failed to provide appropriate information or that the manner of presentation was unsatisfactory or insensitive. Gordon & Kutner (1980) describe a study with 100 families of mentally retarded children. Almost half of the families were critical of doctors' diagnoses and prognoses. Complaints ranged from lack of interest and bluntness by the physician, to claims of unfairness in predicting the future and a tendency to rush hospitalisation. It can be seen, then, that dissatisfaction with specialists is not restricted to the present respondents and that a number of both objective and subjective factors are likely to affect relatives' perceptions of specialists. The support needs of families during stressful events, however, are very real and need to be met.

Relatives' complaints about lack of head injury information feature prominently in the literature (e.g. Crawford, 1983). The present study supports these previous findings. As Steinhauer et al (1980) point out, what the family hears and understands may differ considerably from what they have been told. They may either hear "what they need to hear", or select or distort what has actually been said. The timing of the information is important, however. Saying too much too soon may cause unnecessary anxiety but the authors consider that, more commonly, too little is said too late, and in too ambiguous a manner. There is also a need to maintain regular contact with the family to establish what they have heard, and how they are coping with day-to-day management and emotional adjustment.

Researchers have frequently commented about the need for family counselling (e.g. Rosenthal, 1984). The present findings indicate that this was a major area of unmet need for both the carers and the patients. Dell Orto & Power (1980) point out that interventions which focus solely on the patient apart from the family system are often limited in their scope as well as

their effect, because disability affects the total family. The provision of group counselling can operate as a counter-force to the family's helplessness, isolation, and desperation in that it brings people together to share individual concerns as well as common resources. The goal of group counselling is to be comprehensive and proactive, rather than limited and reactive. As well, a multidimensional model provides systems of alternatives and supplementary groups so that family members can respond to their individual as well as collective needs (e.g. client/patient group, parent group, spouse/marital group, and so on). Family therapy can also complement formal rehabilitation efforts. Many family problems are associated with the process of the grieving cycle. For example, Perlesz & Furlong (1989) consider that family members need to be told that "if you don't grieve you will eventually come to grief". Family denial can be reframed in positive ways, and changed identity issues within the family can be addressed. The findings from the present study indicate that the unmet counselling needs were not confined to the patients and the carers, but that other family members such as children and parents had also required assistance. As well, one carer felt that her head-injured husband had needed a male counsellor, and another parent commented that a "buddy system" may be needed for the head-injured patients. In a broader context, there has also been a repeated call for a holistic, family-oriented approach to rehabilitation with less emphasis on the purely physical rehabilitation of the patient (e.g. Vogenthaler, 1987a). The present findings also support this call.

The former life styles of the patients and their carers had changed dramatically in many cases. All the patients and over half of the carers had changed their former leisure interests. Somewhat surprisingly, the reasons given for the patients' leisure changes were mainly those of physical handicap, rather than psychosocial difficulties. In a study by Oddy & Humphrey (1980), patients' failure to resume leisure activities did not appear to be the result of physical disability. The majority of

the respondents also reported changes in former marital or parental roles. There were financial worries and some of the carers had given up their previous occupations to care for the patient. Two spouses had taken up employment after the injury for financial reasons. Three of the patients were married at the time of injury and one was separated. The separated patient was now divorced, and one married respondent was now living apart from her husband. The remaining two spouses considered that their marriage was no longer a partnership. Sexual difficulties were reported by all three married respondents. One had experienced conflict with her husband's parents who were reluctant to concede that she was "in charge". Jealousy or conflict between parents and the spouse of a head-injured patient has also been reported in other studies (e.g. Perlesz et al, 1989; Rosenbaum & Najenson, 1976). Of the parents, three fathers and one mother had reached retirement status and could scarcely have anticipated a resumption of a parental nurturing role to a formerly self-sufficient son or daughter. The retired fathers, however, were in a position to assist their wives with the patient's care. These findings suggest that the cumulative effect of the many life style changes is likely to mediate carers' stress, and certainly to require significant family adaptation. The requirement for this adaptation reinforces the need for family support and counselling. Spouses or parents not accepting of the nurturing role are likely to experience additional stress.

Some previous research has indicated that spouses may experience more stress, or at least have different sources of stress, than do parental carers of head-injured persons. The small number of married respondents in the present sample precludes conclusions but the loss of previous partnership relationships, additional domestic/business responsibilities, conflict with in-laws, and sexual difficulties, were features unique to the married respondents. Additionally, one spouse reported that, unlike most of the parents, she did not have an uninjured partner for

support. All of the spouses in the present study were female. One could speculate that, in the case of head-injured wives, the husbands may report different reasons for distress and/or that the role relationships would suffer less change. The literature does not record the experiences of male spouses as a separate group. This would constitute an interesting area for research. Some research has tended to focus on divorce as a measure of spouses' distress (e.g. Thomsen, 1974), while other studies have measured stress levels. It has been found that stress levels generally appear not to distinguish spouses from parents (e.g. Brooks et al, 1987a). In the present study, the spouses' mean rating of overall distress was no higher than that of the parents, although the sub-group was very small.

Over half of the respondents considered that either there had been no real change to the overall family unit, or that the patient's injury had actually improved or strengthened the inter-family relationships. Most of the earlier problems concerning the patients' siblings or children had been resolved, although lack of sibling support was still a problem for one patient. This suggests that the majority of the family units were functioning relatively soundly pre-injury and were thus able to withstand the later impact of the family member's injury.

The occupational outcome for the present sample was slightly better than expected when compared to previous research which indicates that half or fewer of moderately to severely head-injured persons return to work. At the time of the interviews, over half of the adult patient sample was working, four of them in full-time occupations. However, only one was working at a level of skill similar to that of the pre-injury occupation. Respondents considered that the majority of the patients had been severely adversely affected by their injuries in terms of occupational aptitudes. The student had been unable to return to any form of schooling. The relatively high proportion of patients who had returned to work, despite their severe injuries, may, of course, reflect in part the rehabilitation efforts at the

facility where they were all treated. Social rehabilitation in many rehabilitation facilities tends to focus on returning the patient to work.

It could have been predicted that having the patient back at work would reduce the carer's stress. In this sample, however, there was no indication either in the respondents' ratings of distress, or in their comments, that this was the case. At least one other study has reported that there is no direct relationship between level of carer's stress and whether or not the patient has resumed work and leisure activities (Oddy et al, 1978).

At the time of the interviews, three of the head-injured subjects were living independently from their parents. The mean level of the relevant carers' distress could thus have been predicted to be lower than their cohorts. This was indeed the case. However, this finding was confounded by the high rating of distress reported by a respondent whose spouse had been in institutional care for the previous year. Similarly, it could have been expected that the mean rating of distress would be highest in the "extremely severe" group. In fact this was not the case relative to the "very severe" group. Two respondents in the "extremely severe" category gave the two lowest ratings for the entire sample. There are various possible explanations for this finding, most of which relate to the smallness of the sample. However, researchers have found that prediction of subjective burden in the relative is not related to objective magnitude of the patient's injury per se (e.g. Brooks et al, 1987a). There has been speculation that this may be due to relatives' lack of objective information about the relative severity of the injury. Alternatively, the carer's own personality may influence his or her subjective perception of changes in the patient and thus the ratings of distress. Some evidence for the latter explanation was found by McKinlay & Brooks (1984).

Regarding the future, only three of the respondents anticipated a deterioration in the patients' current condition. The majority were optimistic of continuing improvement in the patient or an increase in the patient's independence. More than half of the respondents expected no change in their role of carer, nor in the level of help and support currently being received by them. Long term provision of care for the patient, however, was a particular concern for more than half of the respondents, as has been found in previous research (e.g. Mauss-Clum & Ryan, 1981). These present findings indicate a continuing sense of responsibility for, and commitment to, the welfare of the head-injured relative.

Perceptions of past events were less positive. Although no specific questions were asked of respondents regarding their experiences in the pre-hospital discharge and early post-hospital discharge periods, every respondent had comments to make about stressful experiences associated with those earlier periods. The events were clearly still vivid in their minds. The common themes are apparent in the case studies: lack of head injury information, confusion over prognoses, concern about patient care in the general wards, lack of personal support during the hospital period, lack of patient and family counselling, and lack of family consultation prior to the patient's hospital discharge. The period following the patient's hospital discharge had been very stressful for the carers, both physically and emotionally. Relative to these findings, the literature records that lack of information about head injury is commonly reported by relatives. Concern about the standard of hospital patient care is frequently expressed as well (e.g. Bray, 1977). The first month after the injury has been shown to produce the highest level of stress in the carer relative to later periods (e.g. Oddy et al, 1978).

In terms of the present, most of the carers appeared to be accepting of, or resigned to, their present situation. Some had learned "the hard way" and two considered that changes in their own personalities had resulted from their experiences. One

respondent commented that there were still good times, and that sharing life with the patient obviated loneliness. Several respondents also commented that the patients themselves realised that they "could have been worse". In one case, the respondent felt that the patient's injury had released him from the need to "prove himself" or compete with his peers. These findings suggest an overall stoicism, resignation, or even (in some cases) positive perception on the part of carers. This philosophical outlook appeared to be shared by the patients in some cases.

It can be speculated that most of the respondents had moved progressively through the "grieving cycle" or the family reaction stages described by Lezak (1986). This sample differed from Lezak's model, however, in that she describes the final stage (approximately two years post-hospitalisation) as one in which the family expects "little or no change" in the patient. In contrast, the majority of the present sample was still hopeful of some form of improvement in the patient. While this may have been merely "wishful thinking" (or denial) on their part, or a response bias to the question, there was reported evidence in some cases of a continuing, if small, improvement in the patient over the previous year or two. In two cases this represented the patient being aware of problems and trying to change. In another, treatment of an alcohol problem had produced some benefits. This finding is in keeping with a study by Thomsen (1974) which also reported some gradual behavioural improvement in relatives five to six years' post-accident. There is a suggestion, however, that either the present respondents were generally more optimistic relative to some other studied groups, or that the qualitative nature of the present research permitted overall expression (and reporting) of positive comments.

Some respondents reported earlier exchanges with hospital and Accident Compensation Corporation personnel, the tenor ranging from assertive to aggressive. In some cases, medical prognoses were disputed, which indicates the possible presence of denial on the part of relatives. As discussed earlier in this chapter,

however, the timing of the information, and its assimilation by relatives, may be critical (Steinhauer, 1980). There were also instances of respondents' distress about the standard of patient care. The literature records that this aspect is frequently of concern to relatives (Bray, 1977). However, one respondent felt that confrontation with professionals and agencies had helped her to dissipate her anger and reach acceptance of the situation. This suggests that the expression of a carer's anger, then, may be uncomfortable for those to whom it is directed (justly or unjustly) but may be of direct therapeutic benefit to the relative.

Respondents frequently reported instances of patients being treated "differently" or with less than respect by others, including professionals. The reported instances included: avoidance of the patient by former friends; people addressing comments to the carer "over the patient's head"; perceptions that others viewed the patient as now being "not all there"; and hospital personnel adopting a "no brain, no pain" approach to patient care during the acute care stage. It was clear that the respondents were very distressed or angry about these incidents. This suggests that perhaps greater public (and professional) sensitivity and awareness is needed and could be achieved through community education.

Two respondents had evolved their own form of behavioural management of the patient. Others referred to attempts to push the patient increasingly towards independence. These skills had been achieved through intuition and experience, and often by trial and error. This finding indicates that both carers and patients would benefit from early and continuing programmes of patient information and management, including techniques of behavioural management. As Godfrey & Knight (1988) point out, rehabilitation efforts often focus on mediation of specific cognitive deficits (despite lack of evidence of efficacy) but that it is the psychosocial factors which are likely to be crucial in rehabilitation efforts.

The cross-sectional nature of the present study meant that, theoretically, the carers' lives were "captured" at a discrete period in their caring role. The questionnaire and interview focussed on the relative present and, to a lesser extent, on future concerns. It appeared clear, however, that the respondents' perception of the present was strongly mediated by past stressful events as well as the relatively more optimistic future projections. The levels of reported stress, then, were not only of a global nature, but also inclusive of the past.

It is appropriate to comment about the present findings in the context of the questionnaire instrument used in the present study. As detailed in the Method chapter, it was derived from an instrument designed for studies in Glasgow. Its purpose was to measure objective burdens (type 1 and type 2) and to establish possible relationships between these objective burdens and the level of the carer's subjective stress or burden. Both the type 1 burden (changes in family routine, family health, housing conditions, financial status, and social and leisure activities) and the type 2 burden (post-traumatic symptoms and changes to the patient's behaviour and personality) were investigated in the present study. However, unlike the Glasgow studies, the obtained data from the present small sample has been examined qualitatively, rather than quantitatively, although simple statistical techniques such as frequency distributions and rank-ordering of means have been employed to indicate trends.

In terms of the type 1 burden, relatively little has been published regarding findings from the Glasgow studies. However, social variables such as availability of confidantes, relationship between carer and patient, and age of carer, have been found to be insignificant as predictors of carers' burden. The results were obtained from analyses of longitudinal studies (Brooks et al, 1987a). The smallness of the present study, of course, precludes this type of statistical analysis. However, at a simple level of inspection of the present data, there were no obvious direct relationships between these same social

variables and the reported quantitative level of the carer's subjective stress. It is to be remembered, of course, that measurement of stress was confined to a single global rating by each respondent. The descriptive comments provided by respondents give a broad picture of the sources of the stress, but not an objective measure of magnitude for each variable.

The published reports of the Glasgow studies have tended to focus mostly on the relationship between the type 2 burden and levels of relatives' stress. When asked for descriptions of changes in the patients, relatives have reported behavioural, mood, and cognitive changes with much greater frequency than broadly physical changes. This was also the case in the present study. However, as Brooks et al (1987a) have pointed out, it is unlikely that there is an exclusive link between the enduring effects of organic brain damage and behavioural or affective changes. The changes may well be mediated by other variables such as frustration on the part of the patient, changes in his or her social and occupational life, and "effort after meaning" by the relative who may now disregard that some of the patient's current problems were present pre-injury. In longitudinal studies, another likely variable is that of changed threshold of tolerance by the relative over time.

The present study found little evidence of a simple relationship between length of the patient's PTA and the carer's rating of distress. The Glasgow analyses of studies, however, found that patient PTAs of over fourteen days resulted in reports of greater medium to high burden in relatives, when compared to groups with shorter periods of PTA. Reports of low burden were similar between both groupings. In the present study, only one patient had a PTA of less than fourteen days and his carer's rating of distress was the median for the total sample.

As has already been reported, the present study found that speech, communication, and associated interactional difficulties featured prominently in the patient changes reported by the

carers. These problems were not listed among the ten most commonly reported difficulties in the Glasgow study which investigated outcomes at five years post-accident (Brooks et al, 1986). In the present study, the questionnaire item relating to patients' moods and behaviours contained different, relatively "neutral" wording and a smaller number of response categories. This obviously makes direct comparisons difficult. However, in the present study, relatives frequently reported other patient changes which were largely in common with the Glasgow study, such as personality change, slowness, poor memory, loss of energy, aggression, and anger. Unlike the Glasgow study, there were no reports of threats of violence or rapid mood change. It is a matter of speculation as to effect of the different wording in the two relevant questionnaires. In the present study, avoiding "leading" questions on the one hand may have precluded a full range of responses on the other.

An important aspect which needs to be considered in the overall context of the discussion is that all the patient sample in the present study had received rehabilitation treatment. In this respect, they were more fortunate than other head-injured persons who live in areas where such treatment is not available. Apart from some respondents' complaints about the availability and quality of physiotherapy, there was general satisfaction about the more physical aspects of the patients' rehabilitation.

This discussion has presented findings in terms of patterns and trends apparent in the data. Although occasional reference has been made to means, the purpose was to indicate trends, rather than present quantitative analyses inappropriate for such a small sample. In presenting grouped results, of course, there is a danger of obscuring individual experiences from which much may be learned. It is anticipated, however, that the individual case studies presented in Chapter 6 will provide a useful source of rich data. Additionally, some of the minority or individual responses have been described in the foregoing discussion.

The present findings can be summarised in terms of the aims of the study. Much of the "world" of the carers is apparent in the reported cross-case findings, and supplemented by individual case data. The major areas of stress for the present carers were identified as: cognitive, emotional, behavioural and social changes in the patient; lack of head injury information; lack of family counselling; unsatisfactory interactions with specialists; changes to previous roles and relationships, and overall life styles; and, distress caused to carers by lack of sensitivity towards the patients by others. Informal personal support from friends and confidantes, and basic practical needs, were largely met, although there was some perceived need for a specialised activities centre. Rural living meant restricted access to facilities. Complaints about lack of head-injury information, particularly at the point of the patient's hospital discharge, were clearly linked to respondents' sense of powerlessness or loss of control over their situation. In some cases, lack of provision of support services at that time served to exacerbate a carer's sense of being overwhelmed by events. Professional hospital support had been withdrawn and all the responsibility now appeared to be the carer's. One carer became very distressed when the patient first experienced an epileptic seizure. She had not been warned it might happen and not given any information about what to do in the event.

Most of the respondents appeared to have accepted their situation or achieved resolution in their own way. Many of the unmet needs for information, support and counselling related more to earlier periods and it was apparent that present overall global ratings of distress also reflected past events.

CHAPTER 8

SUMMARY AND CONCLUSIONS

This final chapter will draw together the previously presented material and summarise the present study's "world" of carers of severely head-injured persons in the community. After examination of the methodological limitations of the present study, there will be discussion of the study's theoretical implications. Finally, practical implications will be discussed, together with the need for further research.

Summary

Previous research has indicated that the psychosocial consequences of severe head injury can have a profound effect on both the patient and his or her family. The present study found this to be the case.

All of the patient sample had experienced both physical and non-physical changes arising from the injury. The cognitive, behavioural, emotional and social changes in the patient were reported more frequently by the carers than other changes. Patients' communication, conversation, and associated interactional difficulties caused the most distress to carers in the present study, together with the social restrictions or isolation of many of the patients.

Apart from three husbands who shared the caring role with their wives, the carers were all women. This may well relate to the fact that the majority of the patients were male. However, the female caring role can also be viewed as an artefact of society's expectation that women will assume or (in the case of parents) re-assume a nurturing role. Some of the women had given up or reduced their previous paid employment to care for the patient.

The carers were not a homogeneous group. There was a range of

ages from thirty-three to sixty-five; some were spouses, the majority were parents, and one was a companion. Geographically, there was a mix of rural, town and city residence.

The coping strategies were many. Two carers reported having changed their personalities. One had become "harder" and less trusting of other people. The other was now more inclined to "let things happen" instead of "making them happen". Other respondents were stoic or displayed acceptance of their situation. There was little evidence of denial on the part of carers. One respondent commented that "it is not possible to delude oneself forever" and another preferred to be "realistic and not hope for miracles". One spouse had found it necessary to consider her own needs and her head-injured husband was now living in an institution. Several carers had evolved techniques of patient management, including pushing patients towards greater independence. The majority worried about the provision of long-term care for the patient but their present roles were mainly stable, with only three carers anticipating a change.

Previous life-styles had been disrupted. There were reports of financial problems. Spouses had taken up paid employment after the patient's injury for financial reasons and/or were shouldering previously shared family responsibilities. Parents who had reached retirement age were now caring for children who had become dependent again. Three respondents had given up their previous paid employment to care for the patient. Over half of the adult patients had returned to some form of work but with reduced skills and stamina in most cases. Leisure interests had changed for all patients and many of the carers. There were altered patterns in carers' friendships. Loss of distant friends had occurred more frequently than loss of close friends, but in two cases the carers had experienced a loss of both types of friendship. Respondents were generally aware that other people had difficulty in relating to the now changed head-injured patient, but they were still hurt. In some cases, carers had made new friends through the head injury support group.

Personal support needs by way of head injury information, family counselling, and satisfying contact with head-injury specialists had not been met in most cases. There were reports of stress-related symptoms in several carers. All the respondents reflected on past stressful experiences.

It is important to note, however, that many carers had positive comments to make. There were reports of changes for the better in two patients, and a continuation of pleasant characteristics in others. Family units, in the main, had remained intact or had actually strengthened. Perceptions of the future were optimistic in that most carers hoped that the patients would continue to improve or achieve increasing independence. Three of the patients were already living independently from their parents, and some others had displayed small, gradual signs of improvement. This was despite the fact that the median length of time since injury was five years. Personal support by way of confidantes was generally met, as were needs for basic practical assistance.

Carers' subjective ratings of distress were confined to a single quantitative global measure which reflected past, present and future perceptions. Overall ratings on the relevant analogue scale were generally high but not consistently related to the objective severity of the patient's injury.

There were similarities with existing research, but also some differences. Similarities included patients' psychosocial changes being reported more frequently by the carers than broadly physical changes, and there being frequent reports of patients' social isolation. As with findings from other research, there were also complaints by carers of lack of head injury information, lack of family counselling, and lack of information and support from specialists. One notable difference related to carers' frequent reports of patients' communication, conversation and associated interactional difficulties. Together with linked reference to the patients'

social isolation, these changes were reported more frequently than other changes causing distress to carers. Patients' communication difficulties have not been reported as being a major problem to relatives in other similar research. Several respondents reported distress caused to them by others' insensitive attitudes towards the patients, again a feature not evident in the existing literature. In contrast to most reported studies, however, a number of optimistic reports were made by the present respondents.

The results from the present study were presented descriptively and in terms of common themes and patterns supplemented by individual case studies.

Methodological limitations

The present sample was small and was deliberately not randomly selected. It comprised a "convenient" research group - that is, the subject sample had all been patients at the same rehabilitation facility. All the patients had experienced severe to extremely severe head injury and had received rehabilitation treatment. The respondents represented only those who had agreed to participate in the research. Their geographical location was restricted to that within a reasonable radius of the researcher's own area of residence. Given these constraints, then, the results cannot be generalised to a universe or population of carers of head-injured persons in the community. Rather, the present results need to be viewed within the context of existing theory and research. Nevertheless, the systematic presentation of descriptive data permits implications to be drawn relative to the group in the present study.

Ideally, a matched control group, or groups, would have been used. Given the limited resources and marked time constraints of the researcher, this was not feasible. An obvious problem associated with the lack of controls, is that it is not clear in

what respects the present sample was similar to, or different from, carers of non-head injured persons. A control group also permits better evaluation of the validity of findings. While the present sample experienced stress, so do other groups who are not in roles of carers. The purpose of the present study, however, was to explore and describe the experiences and concerns of the present group of carers and to provide data from which hypotheses can be generated.

Relative to stress, the use of a single global quantitative measure of the carer's stress is likely to have been inadequate. A more subtle instrument than a simple rating scale is seen as desirable. However, a lengthy or time-consuming instrument would need to be considered in terms of respondents' tolerance for prolonged interviews. This aspect was a major reason for not including a comprehensive stress measure in the present study. In future studies, measurement of carers' stress-related symptoms by instruments such as brief anxiety and depression scales may produce additional valuable information. Appropriate instruments to measure patients' stress could also be considered.

Another methodological issue involving the reliability and validity of the data, concerns the method of data collection by means of an interview and the questionnaire instrument. Many of the closed response items in the questionnaire called for retrospective information. This may have involved selective remembering on the part of respondents, or called for information about which their memory had become unclear. Additionally, respondents were reporting about the patients in many items, and they could report only about what they knew, perceived, or had remembered. However, medical and some historical details were obtained from patients' medical records, including the measures of PTA.

The use of rating scales relative to some of the questionnaire items also raises the question of response bias, in that respondents may have had an individual tendency to rate

consistently towards a particular section of the scale. Relative to the open-ended questions and the free comments, some response biases may also have been present. The nature of the research itself was sensitive and some of the questions may have evoked an emotional reaction which affected the respondent's reply. A further bias may have been present if there was a desire by some respondents to present socially acceptable responses to questions. This is also linked to the effects of the interviewer's personality on the respondents. For example, there may have been reluctance on the part of respondents to criticise agencies and professionals, to admit to lack of personal support from family and friends, or to complain about the caring role. Responses may have been presented in terms of what the individual respondent perceived as being what the interviewer "wanted to hear". In the present research, every endeavour was made to adopt a tactful and relaxed approach to interviewing, and to assure respondents of the confidential nature of their replies and comments.

Another potential source of bias needs to be considered: given that a substantial number of the respondents belonged to the same head-injury support group, the influences of group contact and discussions may have affected an individual's perceptions of her own experiences. For example, there may have been subjective assessment of experiences as being better or worse than those of others, with a resultant bias in given responses to questions.

As with all single measure designs, data obtained from a single interview is also subject to bias from a momentary response set of the respondent. Momentary moods and feelings can affect subjects' interview attitudes and responses. Recent, or not so recent, experiences can also affect responses. For example, in the present study, respondents frequently recalled past stressful events which may have influenced their responses to questions relating to the present. Conversely, at the time of the interview, some may have just spent a particularly relaxed or

happy day with the patient.

Another methodological consideration relates to the analysis of data. In the present study, with its qualitative approach, this was done descriptively by systematically reporting frequencies and occasional measures of central tendency. The weakness of the descriptive approach, of course, is that it lacks the rigorous and sophisticated analyses of the quantitative method. For example, in the present study, it is possible only to speculate about the effect of the various independent variables on the dependent variable (the carer's stress). The quantitative method may be more analytically accurate and reliable. A strength of the present multiple case study design, however, is that group results do not mask individual differences. The construct validity and reliability of the present qualitative data was monitored by the evidence of multiple instances of particular constructs. Additionally, however subjective the findings may have been, they nevertheless constituted reality for the respondents. The vivid and varied material presented in the individual case studies provides a rich, descriptive base from which hypotheses can be generated and subsequently tested by quantitative methods.

The primary aim of the present study was to explore and describe. Given the relative paucity of studies relating to families who care for severely head-injured persons, the multiple case study design was chosen as being the most appropriate for the present research. It is not seen as better than, but as complementary to, other methodological designs.

Theoretical implications

There is no comprehensive or unified theory which relates to the area of the present study. This can be largely attributed to past lack of research, although there has been a growing interest over recent years.

Various longitudinal and cross-sectional studies have produced some consistent findings: emotional and behavioural changes in head-injured patients cause more distress to families than physical changes; spouses appear to experience different sources of stress than parents, and (in some studies) the divorce rate is high; unmet support needs may place carers at greater risk of increased stress, and so on. However, these studies have largely investigated effects and outcomes. There is a dearth of comprehensive theory to offer predictions and explanations.

An essential difficulty in prediction is that carers' stressors occur not as single events but in the form of inter-related clusters. The value of cross-sectional studies, including the present study, is that descriptions of the various stress factors are provided. For example, in the present study, informational and counselling needs had not been met, and lack of sensitivity by others towards the patient caused distress to carers. Longitudinal studies can measure the impact of selected stressors over time, but results can obviously be confounded by changes to (or the disappearance of) previous stressors, or the advent of a new set. For example, in the present study, the recent occupational retirement of one of the carers' husbands (not head injured) had resulted in increased opportunity for conflict between the father and his head-injured son. This was stressful for the carer. As well, many of the distressing events described by the respondents had occurred in earlier time periods. In the latter regard, it could be seen that these events constituted challenges to the respondents which, if met successfully, resulted in their being better able to cope with subsequent stressful events.

Some independent variables have been examined empirically in relationship to the dependent variable of the carer's stress. For example, Brooks et al (1987a) have found no significant relationship between the level of carers' stress and the following variables: the objective severity of the patient's

injury per se; the absence of confidantes; type of relationship to the patient; and, the age of the carer. Other research has found some evidence for the effects of the carer's own personality on his or her perception of subjective stress (e.g. McKinlay & Brooks, 1984). However, apart from the relationship of a carer to a distinctively head-injured person, these results can be seen as also potentially applicable to other people caring for disabled individuals in the community.

What is unclear, then, are the factors that distinguish carers of head-injured persons from other groups. There have been contradictory findings in studies that have used control groups (e.g. Rosenbaum & Najenson, 1976; O'Brien, 1987). There appears to be a need for a general theory of stress as it relates to people in caring roles. This could be derived from research already undertaken with various other groups. Applied research would then be in a position to identify the unique stressors (if any) for carers of head-injured persons. The findings of the present research may provide some useful indicators. For example, the psychosocial manifestations of head injury can produce generally unpredictable behaviour in the patient. He or she may demonstrate a range of physical and behavioural deficits which are not easily defined or "labelled" by others. As well, the sudden emotional/behavioural changes in the patient may provoke insensitive responses on the part of others who perceive the head-injured person as now being "not all there" or "different" from the former person. In the present study, there were comments by respondents about their being embarrassed by patients' behaviour, or being hurt and angry by other people's insensitivity towards the patient. Overall, then, a unique feature of head injury itself is that it encompasses both physical and non-physical disability. The changes occur suddenly and dramatically, as in all accidental events, but the range of outcome is generally broader than that experienced in other sudden disability.

A number of well-known models of stress already exist in the literature (e.g. Lazarus, 1966). Stress is a multi-dimensional phenomenon which can be studied from a number of points of view. The existing head injury research has generally adopted a psychosocial focus. If the role of carer is considered in occupational terms, however, the theory of Herzberg (1974) which describes "hygiene" factors in the workplace could be considered in a modified form. In terms of the carers of the head injured, it could be proposed, for example, that the absence of certain factors (e.g. practical support needs) causes stress, but that the provision of the same factors may not necessarily increase the carer's wellbeing. Conversely, occupational "motivators" in the caring role need identification (i.e. why do carers remain in the "job" and what constitutes their "job satisfaction"?).

The groundwork for further research has been provided by researchers in the field. This research has been valuable because, like the present research, it has taken place mainly in the context of "real life" situations and has taken account of a myriad of factors. What is now needed is the formulation and testing of hypotheses, and a systematic approach to the formulation of models and theories which predict and explain. Some tentative hypotheses are suggested from the present research. Firstly, it can be proposed that carers have a need for more personal control over their situation. Therefore, if they receive appropriate information and personal support, and are included in the rehabilitation "team", less stress may be experienced. Secondly, some carers will have better (or more) coping resources than others. Therefore, if their existing coping skills are explored early in a counselling context, and added to where necessary, stress may be reduced. Thirdly, early identification of pre-morbid personality factors in both the patient and carer, and analysis of the family composition and structure, would permit proactive measures designed to help "at risk" families. The result would be to reduce the incidence of family disintegration. In the context of this discussion,

however, it is acknowledged that carers need to have choices. Several of the respondents in the present study described themselves as being "private persons" or expressed a wish to retain their independence.

Practical implications

The findings of the present study have some practical implications which will now be discussed, and suggestions and recommendations made.

One of the major findings was that of complaints by the majority of respondents that there had been a failure to provide them with satisfactory head injury information. Additionally there was perception that prognoses had sometimes been inaccurate or confusing. Other related studies have produced similar findings (e.g. Crawford, 1983).

It cannot be stated, however, that these complaints are confined to head injury groups. The literature records that similar dissatisfaction has been reported by families who have members disabled from other causes, including chronic illness (e.g. Harrison, 1977). Research by Cartwright & Anderson (1981) found that patients express more dissatisfaction with the information they receive from doctors than with any other aspect of medical care. In successive studies, Ley (1983) found that many clinicians fail to give patients information in areas where they would like it. However, although patients' satisfaction is related to the amount and content of the information provided, there is also a link to the extent to which the patient understands and remembers information. In this regard, Tuckett et al (1985) found that majority of patients remembered and made sense of most of the key points their doctors made, but with a proviso that there were no differences at any stage between the views of doctor and patient. As Ley points out, contextual factors such as the physical setting, and the individual characteristics of the patient, also play a part. The studies

discussed had examined doctor-patient relationships. There are obviously additional factors to be considered in the context of the present study: for example, the interaction between family member (not patient) and medical personnel. Additionally, the relative may be in a phase of denial, and almost certainly experiencing stress. It can be seen, then, that consideration needs to be given by medical personnel not only to the content of information provided to relatives, but also the timing of this information and the context in which it is delivered. Reinforcement of earlier information may be needed, and regular contact maintained with relatives to ensure that what is said is being heard and understood.

In the present study, there was reference by respondents to factors such as: their right to have information; not really knowing what to ask; disputing the prognosis; needing basic information in the form of written material; having to resort to obtaining information from other sources; and, an expressed need to be in control of the situation when the patient was discharged home by having information about what to expect and how to deal with it. There was concession that some problems "may never come to pass" but this was generally seen as preferable to being "left in the dark".

It is recommended, then, that consideration be given to providing relatives with basic written information in the period immediately following the patient's injury. From this, more definitive questions could be asked by relatives (as needed) regarding the individual patient's condition and prognosis. The provision of written material would obviously overcome the problem of their not remembering verbal information; it is also a source of information that is not time restricted and can be referred to as needed. Additionally, further supplementary and detailed written material would assist relatives at the time of the patient's hospital discharge. It is seen that the provision of information is a medical responsibility. However, head injury support groups are in a position to provide both informal

information and personal support, and would be a useful source of reference as to the content of written material.

Several respondents in the present study felt that their experiences with head injury specialists had been unsatisfactory. This complaint took two forms: the lack of provision of satisfactory information (which has already been discussed); and, a perception by some respondents that the specialist was either impersonal or insensitive. The latter area represents support needs and is worthwhile taking into consideration by medical personnel dealing with the relatives of head-injured patients. There were comments, also, that the focus is on the patient during the hospital period, and that relatives' own support needs can be overlooked. In some cases, respondents were reluctant to ask for help or did not perceive until later what their earlier needs had been. This area is relevant to social workers and others who are in a position to maintain regular contact with relatives.

Another important area of reported unmet needs was that of psychological counselling for both patient and the family. Once again, other studies have produced similar findings (e.g. Livingston, 1986). Apart from its role in the provision of support to the family, family counselling can also be viewed within the context of holistic rehabilitation which takes account of the important role a family plays in the patient's rehabilitation. In effect, it is the family which is being rehabilitated. The need for a move away from the traditional focus on patients' physical rehabilitation is noted frequently in the literature (e.g. Oddy et al, 1978). In the present study, several carers commented that the patient had been in need of professional counselling or (in one case) that he would benefit from a "buddy" system. In recommending that policy decisions urgently take into account this presently unmet need for family counselling, it is acknowledged that there may be a present shortage of resources. However, future planning and the setting of priority goals may overcome current difficulties.

Programmes based on successful overseas models and experiences are indicated (e.g. Dell Orto & Power, 1980; Perlesz & Furlong, 1989).

Several respondents had experienced distress because of perceived insensitivity by others towards the patient. There were reports of patients being treated "with less than dignity", or receiving little attention and concern from hospital personnel and agencies. This was perceived by relatives to reflect attitudes of "no brain, no pain" or a taking advantage of the patient's relative helplessness (especially in the acute stage of hospital care). Other respondents reported that visitors "talked over (the patient's) head" to the relative, or now viewed the patient as being "not all there". One respondent commented that people would cross to the other side of the street to avoid having to interact with her husband. At the same time, it was often acknowledged by respondents that lay people simply did not understand about the effects of head injury, particularly where the patient did not display many physical symptoms. In many cases people meant well but were uncomfortable in the presence of the patient. A potential solution to this problem is an educational one, perhaps through the head injury support groups, or other agencies which promote awareness of disability. Apart from visual presentations and discussions, the availability of simple, written material may be appropriate. Grants from appropriate agencies could be sought if financial assistance is required.

The study's findings indicate that an increased level of concern and support for the family during the early period following the patient's hospital discharge may be required. Additionally, some respondents considered that there had been insufficient discussion with them before a decision was made to discharge the patient home. It can be seen that post-hospitalisation is the period when professional hospital support is withdrawn and the relative has to assume full responsibility. Other studies have found that the early post-hospitalisation period is the most

stressful period for relatives (e.g. Davis, 1980). In the present study, the carers had found this time to be both physically and emotionally demanding. The personal assistance required by the adult patient (sometimes a large, heavy man) had been very taxing on the carer. Some respondents had received assistance from the district nursing service or home help but others had not been aware that such assistance was available. It is noted that one respondent was reluctant to ask for support, on the basis of "not wanting anything unless it was offered". A full assessment of the home situation, and the carer's physical and emotional capacity, together with provision for practical support, then, is seen as being a necessary requirement before the patient's hospital discharge. This would need to be considered within the context of policy and community-based resources.

Apart from a few complaints about physiotherapy treatment, the respondents were generally satisfied with the relatively physical focus of the rehabilitation measures. It was the lack of information and counselling that concerned them more.

As discussed in other parts of this report, some respondents had evolved techniques of patient behavioural management, largely on the basis of intuition or trial and error. To return to the theme of holistic rehabilitation, the inclusion of family members in planned programmes of patient management would no doubt benefit both the patient and the carer. Linked to this, is the need to provide full information to the relative. Without such information, carers may set goals for the patient which are unrealistically too high or too low. One respondent in the present study was concerned about "pushing (the patient) too hard" and was aware of the very fine balance involved.

Similarly, available programmes of stress management for the carers would be of assistance. Some respondents had found their own ways "to keep sane" - for example, by working in paid employment or becoming involved in a head injury prevention

project. However, techniques of relaxation and other measures to reduce stress would provide carers with personal resources. The multidimensional group counselling model described in Chapter 7 (Dell Orto & Power, 1980) which provides for individual needs by means of supplementary groups (e.g. groups of spouses, groups of parents, and so on) may also be effective and provide group support. While the head-injury support group was helpful to the present respondents, it operates at a relatively broad and informal level.

Agencies such as the Accident Compensation Corporation received negative comments from several respondents. The complaints centred mainly around lack of personal support for the carer, or lack of information concerning financial entitlements. Some felt that there was too much concern for bureaucratic procedures at the expense of a more personal approach. This is worthy of note by both ACC and by other agencies.

There was comment by several respondents that a need existed for facilities such as activities centres which catered for the special needs of head-injured people. The lack of virtually any type of facility was a particular problem in rural areas. Where sufficient numbers of head-injured persons live in a particular community, provision of suitable activities and social programmes should not be too difficult if sufficient resources are available. In the more isolated rural areas, where travelling would preclude active participation in city facilities, some imaginative improvisation may be called for. For example, one could investigate the activities of local groups and clubs, and seek appropriate, sympathetic employers who would provide simple, unpaid activities within a workplace.

The preceding discussion has concerned itself with the common themes expressed by a substantial proportion of the respondents. There were, of course, individual experiences and concerns which were not in common with other respondents. These are to be found in the individual case studies, and occasionally commented upon

illustratively in other parts of this report. Had the sample been larger, there may have been other common themes, so that the individual reports cannot be entirely dismissed because of lack of group consensus.

In the context of the present discussion, the matter raised earlier in this report of possible targeting of respondents' anger towards agencies and personnel needs to be considered. There may or may not be justification for the expression of such anger. However, the question of provision or non-provision of certain defined services and types of support is an area that is open to objective verification.

It is hoped that the various above recommendations and suggestions will be considered. Many of the respondents in the study expressed a wish that their taking part in the research would result in benefit to others in a similar situation.

Future research

Some directions for future research are indicated in the present report's earlier discussions.

In general terms, of course, there is an obvious need for future research simply because the area has received relatively much less attention than head injury itself. It is seen, however, that future research requires better direction by way of systematic construction of models and theories. In popular terminology, there is no need to "re-invent the wheel". For example, existing psychological theories could be considered in a adapted and modified form and used to provide a framework. The findings from other research with groups who care for non-head injured persons could also provide a useful data in the forming of model frameworks. For example, the literature indicates that research has been carried out with groups who care for persons with chronic or progressive illness, intellectually handicapped children, cancer and stroke victims, and the elderly. Theories

of stress such as that of Lazarus (1966), or occupational models such as Herzberg (1974), were discussed earlier in this chapter.

The present study, like some others, looked at the level, or degree, of stress experienced by the carers. There is indication that the content of this stress needs further investigation, particularly in the case of spouses versus parents of head-injured persons. Additionally, it can be seen that some stress factors fall outside the area of the carer's control (e.g. the injury itself, medical care, and provision of services), while others fall within it (e.g. coping strategies, self-imposed social isolation). It would be helpful to distinguish these in terms of strategies for intervention. Identification of specific patterns of stress-provoking events in both early and later stages would permit better targeting and timing of strategies. For example, the present research identified that the provision of appropriate information and family counselling support were needed in relatively early periods following the patient's injury. The personal and financial support needs of relatives also appeared to be frequently overlooked in the hospital setting. The inclusion of family members in rehabilitation programmes and overall decision-making may provide them with a sense of greater control over events and reduce potential feelings of helplessness.

Pre-morbid factors such as the personalities of both the patient and the carer, together with their demographic characteristics, constitute an area for further research, as does pre-morbid family functioning. The identification of these variables and their relationship to later events could provide useful predictive indicators. For example, early identification of "at risk" families would enable early planning for appropriate counselling and support. There is a further need to establish how and in what ways families react to the impact of a family member's severe disability. Factors such as individual and whole family reactions, coping styles and strategies, and the processes of resolution achievement merit investigation. Carefully designed

cross-sectional and longitudinal studies which permit cross-comparisons are indicated.

Research into the identification of stress factors, and studies which measure the effects of various events on level of stress, provide very useful data. However, such research may not be of direct benefit to those in the caring role unless, as a result, strategies are planned by professionals and agencies to remove, reduce or alleviate the experienced stress. Additionally, studies which include "normal" controls would help identify the magnitude of carers' stress relative to the general population. Other control groups could include the orthopaedic and spinal cord injuries groups already used in some studies, or other groups such as alcoholics or intellectually handicapped persons. Matching samples in terms of age distributions may pose problems, since the head-injured are characteristically young.

Another area of potential research is that of measuring the effectiveness of training relatives in programmes of patient behavioural management. The present findings indicated that there is a need for this type of training. A design using control groups would provide useful data relative to future policy planning by rehabilitation facilities. There is an insistent call for holistic rehabilitation programmes but research in support of this call is lacking. The factors that distinguish head-injured patients who have received intensive rehabilitation treatment from those who have not, is also an indicated area of research.

From a methodological perspective, there appears to be a case for criticism relative to shortcomings in some research studies (e.g. Godfrey et al, 1987; Oddy, 1984). For example: different criteria have been employed for assessing head injury severity; some studies have focused on psychosocial outcomes relative to very severely head injured patients, while others have used mixed groups (making cross comparisons difficult);

demographic variables are sometimes under-reported (also creating a problem with cross comparisons); there is often variability in subjects' age range; the role of pre-morbid history (both patient and carer) has either not been taken into account, or there has been over-reliance on subjective retrospective ratings; very few studies have used control groups; and, the choice of statistical techniques used to analyse data may be sometimes inappropriate relative to the complexity of the multi-determinants of head-injured patients' social functioning. For example, Godfrey et al (1987) consider that the univariate statistics employed in most of the relevant studies to date present two difficulties. Firstly, the social functioning of head-injured adults is likely to have multiple determinants and multiple measures are therefore appropriate. Secondly, multiple univariate comparisons are made between groups. The larger the number of these comparisons, the greater the chance of Type 1 statistical error.

As research continues, and perhaps takes place in a variety of countries, cultural aspects will need to be considered. For example, rehabilitation efforts to promote maximum independence for the patient may actually create family dysfunction in certain cultures. Additionally, family expectations of the patient may vary greatly, depending on variables such as sub-cultural factors and socio-economic status.

Essentially, the rationale for further research into the psychosocial consequences of head injury can be viewed from two different perspectives. Firstly, from an acknowledged concern for the relatives of severely head-injured persons, and a perception that there is a need to provide support and family rehabilitation which will benefit both patient and family. Secondly, from a desire to measure the effects of head injury itself by investigating the head-injured person's psychosocial functioning within the context of the family. Given this dual role, consideration needs to be given to research designs so that primary aims are clearly identified and pursued. For example,

too broad a focus may produce a range of data which, while interesting, does not clearly identify problems specific to either patients or their carers. In this regard, designs which involve interviewing both patients and carers may need to systematically address a relatively small number of defined variables. Where direct interviewing of patients would be inappropriate, more indirect measures of patient behaviour could be considered: for example, observational measures.

Although it does not relate directly to the area of the present study, it may also be appropriate to comment that the best overall solution to head injury is prevention. Demographic data indicates that young people injured in road accidents constitute the greatest proportion of the head-injured population.

The literature records the findings of a number of valuable studies which have all contributed to our knowledge and understanding of the psychosocial consequences of head injury. Future research will no doubt continue to add to the existing body of knowledge. It is hoped that, in a small way, this present study has also contributed to that knowledge.

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APPENDIX A

PALMERSTON NORTH HOSPITAL MEDICAL REHABILITATION UNIT

The following brief summary provides background information about the development and present operation of the Rehabilitation Unit. The information was kindly provided by Dr. Norma Carter.

The Palmerston North Hospital Medical Rehabilitation Unit is a comprehensive unit addressing many aspects of rehabilitation. Patients are mainly in younger age groups (i.e. under 75 years). The Unit opened in 1972 as a pilot scheme and is unique in New Zealand in terms of the wide range of rehabilitation services it offers, including work assessment and placement. The Unit's main objective is to assist patients to achieve maximum fitness and independence in order to return home to domestic duties, work, leisure, or retirement activities. Where this is not possible, the emphasis is on the patient's adaptation to his or her disability and in finding appropriate accommodation and day-time activities.

The Rehabilitation Unit accepts patients with a wide range of physical and intellectual disabilities, including head injuries. The Unit's team consists of the doctor, nurse, physiotherapist, occupational therapist, speech therapist, social worker, clinical psychologist, workshop staff, and a job placement officer. The various members of the team each have their own expertise to offer. All head-injured patients referred to the Unit initially have full assessment by the rehabilitation team, in order to establish the full extent of the physical, intellectual and emotional disabilities. A rehabilitation programme is then designed to address all the problem areas by means of therapy, counselling, or adaptation of the patient's home or work environment. Family members are often included in the programme. In a ten-year period from 1976 to 1985 inclusive, 78 patients with head injuries were treated at the Unit.

APPENDIX BQUESTIONNAIRE USED IN THE PRESENT RESEARCH

A copy of the questionnaire instrument used in the present research is appended. It contains 85 items and is divided into seven sections. Full details of the questionnaire are contained in Chapter 5 of this report. A copy of the original Glasgow checklist from which the present questionnaire is derived is contained in Appendix C.

CODE
 Date of Interview.....
 Time commenced.....
 Time concluded.....

HEAD INJURY RESEARCH - CHECK LIST

HISTORICAL DATA

PATIENT

1. Patient's date of birth
2. Patient's date of accident
3. Sex Male/Female
4. Marital Status Single
 Married
 De facto.....
 Separated.....
 Divorced.....
 Widowed.....
 Child.....
5. Length of hospitalisation following injury
6. Length of PTA
7. Assessment of severity of injury

8. Was the patient suffering from any serious illness or disability before this accident (including any previous head injury)? If so, describe.

9. Educational level of patient at time of accident
 Primary school
 Secondary school to Form
 S.C.....
 U.E.....
 6th Form Cert.....
 University Qualifications.....
 Other Tertiary Qualifications.....
 Trade Qualifications

10. Pre-injury occupation of patient
Years of work
11. Did the patient drink before the accident?
Abstained.....
Occasionally.....
Social.....
Heavy.....
Alcoholic.....
12. Did the patient use drugs or other substances (including
prescription drugs) before the accident? (specify class
of drugs used)
No.....
Occasionally.....
Frequently.....
Heavily.....
Class of drugs used
13. Had the patient been involved with the police at any time
before the injury? If yes, detail.
Yes.....
No.....
Detail.....
.....
.....

INFORMANT

14. In what way is informant related to patient?

Husband.....
Wife.....
Mother.....
Father.....
Brother.....
Sister.....
In-Law.....
Other relative.....
Non relative.....
Paid attendant carer.....

15. How long married or living togetheryears
at the time of accident?

16. Age of informantyears

17. Who has MAIN responsibility for caring for the patient?

Informant.....
Other.....

18. Who lives in the household? (list with ages and
relationship to patient)

ACCIDENT

19. Circumstances of injury (describe)

20. How injured

At home.....
 At work.....
 MVA (pedestrian).....
 MVA (passenger).....
 MVA (driver).....
 Motorcycle (driver).....
 Motorcycle (passenger).....
 Bicycle.....
 Sport/Recreation.....
 Assault.....
 Fell.....
 Other.....

21. Culpability (informant's estimation)

Clearly patient's.....
 Clearly other person's.....
 Completely accidental.....
 Uncertain.....

22. Had patient been drinking at the time of the accident?

No alcohol
 Some alcohol.....
 Drunk.....
 Not known.....

23. Had patient been using drugs, prescription medication, or other substances at the time of the accident?

Yes (specify).....

 No.....
 Not known.....

POST-ACCIDENT

24. Is patient physically able to get about?

Yes - independent.....
 Yes - uses stick/crutches
 Confined to wheelchair
 Confined to bed

25. If "independent"- does patient need assistance or supervision to get about?

Wholly independent.....
 Needs assistance.....
 Needs supervision.....

26. As a result of the accident, has the patient experienced any physical problems over the past year?

No.....
 Yes.....

If yes, detail:

Tetraplegia.....
 Paraplegia.....
 Hemiplegia.....
 Arm weakness.....
 Leg weakness.....
 Sight.....
 Hearing.....
 Speech.....
 Taste.....
 Smell.....
 Balance.....
 Dizzy spells.....
 Fits (seizures)....
 Headaches.....
 Incontinence.....
 Other physical disability

27. Have there been changes in the patient's moods and behaviour since the accident? If so, please describe the direction of such changes (consider moods/behaviour over the past year). PRESENT RESPONDENT WITH SCALE (App.1)

Energy level.....Before.....Now.....
 Sleeping patterns.....Before.....Now.....
 Eating and drinking patterns...Before.....Now.....
 Communication and conversation.Before.....Now.....
 Self-control.....Before.....Now.....
 Co-operation.....Before.....Now.....
 Personal habits/daily routines.Before.....Now.....

Sexual activity.....	Before.....	Now.....
Depression.....	Before.....	Now.....
Anxiety.....	Before.....	Now.....
Patience.....	Before.....	Now.....
Tolerance.....	Before.....	Now.....
Judgement	Before.....	Now.....
Insight.....	Before.....	Now.....
Memory.....	Before.....	Now.....
Concentration.....	Before.....	Now.....
Interaction with others.....	Before.....	Now.....
Independence.....	Before.....	Now.....
Responsibility.....	Before.....	Now.....
Self-esteem.....	Before.....	Now.....
Other.....	Before.....	Now.....
.....	Before.....	Now.....

28. Since the accident, has the patient been involved with the police? If yes, detail.

Yes.....(detail).....
 No.....

AGENCIES/PROFESSIONALS

29. How often does the patient see his/her GP?

Irregular contact.....
 Regular contact, not head-injury
 related.....
 Regular head injury contact - consultations

 Regular head injury contact - repeat prescriptions
 only
 Regular statutory examination only (for ACC or DSW
 medical certificates).....

30. Please rate the quality of help and support given by the GP
 in relation to the head injury. PRESENT RESPONDENT WITH
 SCALE (Appx. 2):

	0	1	2	3	4	5	6	7	8	9	10

Poor											Outstanding
	-	-	-	-	-	-	-	-	-	-	-

31. Since hospital discharge, has the patient received treatment
 or assistance from the following people or agencies? If so,
 please rate the quality of the help and support provided.
 PRESENT RESPONDENT WITH SCALE (Appx. 2):

	0	1	2	3	4	5	6	7	8	9	10

Poor											Outstanding
	-	-	-	-	-	-	-	-	-	-	-

Rehabilitation Unit doctors.....
 Specialist (e.g. neurologist).....
 Occupational therapist.....
 Physiotherapist.....
 Speech therapist.....
 Psychological assessment.....
 Psychological counselling.....
 Hospital social worker.....
 District nurse.....
 Sheltered workshop or agency
 (e.g. Crippled Children Society).....
 ACC Rehabilitation Co-ordinator.....
 DSW social worker.....
 Home help.....
 Child care.....
 Other.....

Comments:

32. For how long was this assistance/treatment received after
 hospital discharge? (Specify in months)

Rehabilitation Unit doctors.....
 Specialist.....
 Occupational therapist.....
 Physiotherapist.....
 Speech therapist.....
 Psychological assessment.....

Psychological counselling.....
 Hospital social worker.....
 District nurse.....
 Sheltered workshop or agency.....
 ACC Rehabilitation Co-ordinator.....
 DSW Social Worker.....
 Home help.....
 Child care.....
 Other.....

Comments:

33. Are there any alterations needing to be done to the home
(or have they been done), because of the patient's injury?

No.....
 Yes, alterations done.....
 Yes, alterations needed.....

Details (including approximate cost).....

34. Has the patient been provided with equipment and various
aids for daily living?

No.....
 Yes.....

Detail:

Have these been sufficient for needs?

Yes.....
 No.....

Detail:

35. Are you receiving any PAID home help assistance?

No.....
 Yes - hours per week.....

36. Who pays for this assistance?

ACC.....
 DSW.....
 Hospital.....
 Other (specify).....

37. Are you receiving any UNPAID home help assistance?

No.....
 Yes - hours per week....

38. Who gives you this help?

Relatives.....
Friends.....
Neighbours.....
Other (specify).....

39. Are you receiving any paid attendant care assistance?

No.....
Yes - hours per week.....

40. Who pays for this assistance?

ACC.....
DSW.....
Other (specify).....

41. Is the paid attendant carer from an agency, or employed privately?

Agency.....
Private.....

42. Is the amount of home help and/or paid attendant care assistance sufficient?

Yes.....
No.....

If no, detail:

CARER

43. Are you still able to confide in the patient about problems?

Not at all.....
 To a limited extent.....
 Yes, fully.....

44. Is there anyone (else) you can talk to?

Never.....
 Only sometimes.....
 Yes - when needed.....

If so, how often do you talk to them?

Very occasionally.....
 At least once a month.....
 At least once every week.....

If so, who is it?

Friend/neighbour.....
 Relative.....
 Other.....

45. Do you have as many friends (both close and distant) as you did before the patient's injury, or have they increased or decreased in number?

Close friends.....
 Distant friends.....

Describe any changes:

46. How often do YOU see your own GP?

Irregular contact.....
 Regular contact.....

If regular contact, ask for specific reason and specify:

47. Do you feel that you have received, or are receiving, sufficient help and support from the following agencies and/or people?

If no, describe in each case what could be improved:

Medical support - GP.....
 - Specialist.....

Hospital Rehabilitation Unit.....
 Information about head injury.....
 Support group (for families of head-injured persons)
 Day-care centre (for patient).....

Sheltered workshop facilities (for patient).....
 Para-medical services (for patient).....
 Professional counselling (for patient).....
 Professional counselling (for yourself).....
 Someone to confide in.....
 Church/Minister.....
 Organised social outings with other families
 in similar situation.....
 District nursing.....
 Hospital social worker.....
 ACC Rehabilitation Co-ordinator.....
 DSW Social Worker.....
 Home help.....
 Child care.....
 Attendant care.....
 Relief care - daily.....
 - weekly.....
 - monthly.....
 - annually.....
 Family support from (those living in house)
 - spouse (not head-injured).....
 - parents.....
 - children.....
 - brothers/sisters.....
 - in-laws.....
 Family support from (those living away)
 - spouse (not head-injured).....
 - parents.....
 - children.....
 - brothers/sisters.....
 - in-laws.....
 Friends.....
 Neighbours.....
 Financial assistance.....
 Other.....

48. Is the patient the same person you knew before his/her injury?

Yes.....
 No, major change.....
 No, some change.....

If no, specify details:

49. Which changes in the patient have been the most distressing for you?

50. Overall, how much strain/distress have you felt because of the changes in your husband/wife/other since the accident?
PRESENT RESPONDENT WITH SCALE (Appx. 3):

0	1	2	3	4	5	6	7	8	9	10

Low										Extreme
-	-	-	-	-	-	-	-	-	-	-

51. Looking into the future, do you foresee any changes in:

the patient?

.....

.....

the level of help and support presently being received by you?.....

.....

.....

your own role as the carer?.....

.....

.....

Comments:

52. If you have any particular concerns about possible future changes, what are they?

FAMILY OCCUPATION/S, INCOME AND LIFE STYLE

53. During the week before the injury, was your husband/wife/other working?.....

Overtime.....
 Full time.....
 Part time.....
 Off work (job open).....
 Unemployed (less than 6 months)
 Unemployed (more than 6 months)
 Retired.....
 Housewife.....
 Student.....
 Child.....

54. During the week prior to this interview, was your husband/wife/other working?

Overtime.....
 Full time.....
 Part time.....
 Off work (job open).....
 Unemployed (less than 6 months)
 Unemployed (more than 6 months)
 Retired.....
 Housewife.....
 Student.....
 Child.....

55. Before the injury, how often was your husband/wife/other absent from work?

Seldom.....
 Occasionally.....
 Frequently.....
 Permanently.....

56. In the last year, how often has your husband/wife/other been absent from work?

Seldom.....
 Occasionally.....
 Frequently.....
 Permanently.....

57. Before the injury, was he/she in regular work?

Yes.....
 No.....

58. In the last year, has he/she been in regular work?

Yes.....
 No.....

59. If working, is his/her present job as difficult as the job he/she had before?

More difficult.....
 Similar/same.....
 Less difficult.....

60. If working, is he/she working for the same employer as before the accident?

Same.....
Different.....

61. How well do you think your husband/wife is coping with the work he/she is doing at present?

No difficulty.....
Some difficulty.....
Considerable difficulty.....
(detail).....
.....

62. Has his/her future work capacity been adversely affected by the injury?

Not affected.....
Mild/moderate.....
Severe.....

Comments:

63. If housewife - before the injury, how did she manage with the housework?

No difficulty.....
Some difficulty (specify).....
.....
Considerable difficulty (specify)
.....

64. In the last year, how has she managed with the housework?

No difficulty.....
Some difficulty (specify).....
.....
Considerable difficulty (specify)
.....
.....

65. If student - before the injury, how did he/she perform at school/University/tertiary institution?

No difficulty.....
Some difficulty (specify).....
.....
Considerable difficulty (specify)
.....
.....

66. In the last year, how has he/she performed at school/University/tertiary institution?

No difficulty.....
Some difficulty (specify).....
.....
Considerable difficulty (specify)
.....
.....
Unable to attend.....

67. Are there any financial problems at present?
- None.....
 Minor ("struggle").....
 Major (threat of legal action).....
68. Did you have any financial problems just before the injury?
- None.....
 Minor ("struggle").....
 Major (threat of legal action).....
69. Is your husband/wife a main earner or contributor to the family income at the present time?
- Only wage/income earner.....
 Chief wage/income earner.....
 Contributory wage/income earner.....
 Self-supporting.....
 Statutory beneficiary.....
 Dependent financially.....
 Other (specify).....
70. Is the patient wholly or partly supported by income from weekly ACC compensation or DSW benefit? (specify which).....
- Not at all.....
 Partly maintained.....
 Wholly maintained.....
71. Before the accident, was your husband/wife a main earner or contributor to the family income? (patient's pre-injury status)
- Only wage/income earner.....
 Chief wage/income earner.....
 Contributory wage/income earner.....
 Self supporting.....
 Statutory beneficiary.....
 Dependent financially.....
 Other (specify).....
72. What effect has the injury had on the family's NET income (take home pay)?
- Little or none.....
 Some.....
 Considerable.....
73. Did YOU work in an occupation before the accident?
- No.....
 Yes, full time.....
 Yes, part time.....
 Other.....
74. Have you given up this employment to care for the patient?
- No.....
 Yes.....
 Reduced hours.....

75. Have you taken up paid employment SINCE the accident?

No.....
 Yes, to help with family finances

 Yes, engaged paid attendant carer
 to care for patient.....

76. Has any additional expenditure resulted from caring for the patient or from the patient staying at home?

(if yes, list and specify)

77. Has the patient changed his/her leisure activities since the injury?

No.....
 Yes.....

If yes, describe changes:

If yes, is this because of:

Financial restraints.....
 Physical handicap.....
 Social withdrawal.....
 Loss of interest.....
 Loss of former friends.....
 Other (specify).....

78. Have YOU changed your leisure activities since the patient's injury?

No.....
 Yes.....

If yes, describe changes:

If yes, is this because of:

Financial restraints.....
 Patient's physical state.....
 Patient's emotional/behavioural state.....
 Patient's need for supervision.....
 Other (specify).....

79. In the last year has anyone in the household had to stay away from work or school to look after the patient?
 (if yes, specify)

No.....
 Yes, occasionally.....
 Yes, 14 days +

80. In the last year, has your household routine been upset as a result of your husband/wife's injury?

No.....
 Yes.....

81. Have the previous roles and relationships in the family undergone change since the patient's injury?

No.....
 Yes, major changes.....
 Yes, some changes.....

If yes, specify details:

82. In your opinion, what effect has the injury had on the relationship/marriage?

No effect.....
 Some effect (specify).....
 Major effect (specify).....

Describe:

83. In your opinion, what effect has the injury had on the sexual relationship between yourself and your partner?

No effect....
 Some effect (specify)....
 Major effect (specify)...

Describe:

84. In your opinion, what effect has the injury had on the family unit?

No effect
 Some effect (specify).....
 Major effect (specify).....

Describe:

85. Are there other issues you feel are relevant but that we have not yet talked about?

Yes (detail).....
 No.....

Describe:

REFERENCE QUESTION 27

APPENDIX 1

0	1	2	3	4	5	6	7	8	9	10

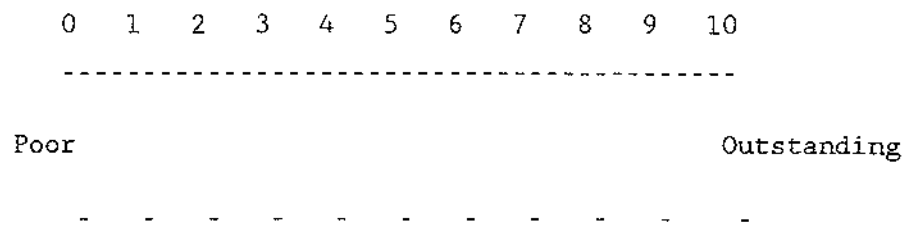
Low										High
-	-	-	-	-	-	-	-	-	-	-

PLEASE CONSIDER EACH MOOD/BEHAVIOUR IN TERMS OF:

1. BEFORE THE INJURY
2. AS IT IS NOW
 (over the past year)

REFERENCE QUESTIONS 30 and 31

APPENDIX 2



REFERENCE QUESTION 50

APPENDIX 3

0 1 2 3 4 5 6 7 8 9 10

Low Extreme

APPENDIX CUNIVERSITY OF GLASGOW QUESTIONNAIRE (CHECKLIST)

The present study's questionnaire was derived from one used in studies by Professor Neil Brooks (and others) of the University of Glasgow. Professor Brooks kindly gave permission for the researcher to use parts of the original questionnaire (checklist) in the present study. More details are contained in Chapter 5 of this report.

A copy of the original instrument is attached.

Date

Column
(Card)

SHHD HEAD INJURY

STUDY - USE OF SERVICE

1. Sex

0 = Male
1 = Female☐ 9 (1)

2. Marital Status

0 = Single
1 = Married/Cohabiting
2 = Separated
3 = Divorced
4 = Widowed☐ 10

3. In what way is informant related to patient?

0 = Husband
1 = Wife
2 = Mother
3 = Father
4 = Brother
5 = Sister
6 = In Law
7 = Other relative
8 = Non relative☐ 11

4. How long married/living together (years)

☐ 12-13

5. Were any marital problems

0 = None mentioned
1 = Problems mentioned
2 = Divorce contemplated☐ 14

6. Establish who has "M" responsibility for caring for patient (ie cooking, washing, supervision)

0 = Informant
1 = Other (specify)☐ 15

7. Age of patient (years)

☐ 16-17

8. Age of informant (years)

☐ 18-19

		2
	Colu	
	(car	
9. Pre injury occupation of head of patient's Household (Code EGSC 1 - 5)	<input type="checkbox"/>	2
10. Educational level of patient	<input type="checkbox"/>	2
0 = Special School		
1 = Normal school until leaving age		
2 = Normal school beyond leaving age		
3 = Apprenticeship etc		
4 = Vocational/College		
5 = University/Professional		
11. Circumstances of injury (Give available details)		
12. How injured	<input type="checkbox"/>	22
0 = In Home		
1 = At work		
2 = RTA (pedestrian)		
3 = RTA (passenger)		
4 = RTA (driver)		
5 = Sport		
6 = Assault		
7 = "Fall"		
8 = Other/Uncertain		
13. Culpability (Informant's estimation)	<input type="checkbox"/>	23
0 = Clearly patients		
1 = Clearly other persons		
2 = Completely accidental		
3 = Uncertain		
14. Had patient been drinking at time of accident?	<input type="checkbox"/>	24
0 = No alcohol		
1 = Some alcohol		
2 = Drunk		

15. Is there a compensation claim outstanding?

0 = Yes
1 = No

☐ 25 (1)

16. If "No" to question 15, ask if one was ever made

0 = Yes
1 = Still pending
2 = No

☐ 26

17. If "Yes" to question 16, ask when it was settled.
(Code number of years post injury)

☐ 27

18. If "Yes" to question 16, ask relative's view
of reasonableness of settlement

0 = Generous
1 = Adequate
2 = Inadequate

☐ 28

19. For how long was patient in any hospital
(number of weeks)

☐ 29-30

SYMPTOMS/BEHAVIOURAL PROBLEMS (OB2)

A) PHYSICAL/SENSORY

20. Is patient physically able to get about?

☐

31

- 0 = Yes - independent
 1 = Yes - needs stick/crutch
 2 = Confined to wheelchair
 3 = Confined to bed

21. If "independent" - does patient need a "helping hand" to get about?

☐

32

- 0 = Wholly independent
 1 = Needs helping hand

22. As a result of the accident has the patient suffered, during the last year, from problems of:-

- 0 = Absent
 1 = Present

Sight

☐

33

Hearing

☐

34

Taste

☐

35

Smell

☐

36

Balance

☐

37

Dizzy Spells

☐

38

Fits (seizures)

☐

39

Headaches

☐

40

Colm.
(Card)

B)

PSYCHOSOCIAL

AS A RESULT OF THE INJURY, DO ANY OF THE FOLLOWING APPLY TO
THE PATIENT OVER THE LAST YEAR?

0 = Absent
1 = Present

- | | | |
|-------------------------------------|--------------------------|----|
| 22. Troubled by noise | <input type="checkbox"/> | 41 |
| 24. Easily tired | <input type="checkbox"/> | 42 |
| 25. Slowed down | <input type="checkbox"/> | 43 |
| 26. Often "Unwell" | <input type="checkbox"/> | 44 |
| 27. Often "Anxious/Tense" | <input type="checkbox"/> | 45 |
| 28. Restless/Wandering | <input type="checkbox"/> | 46 |
| 29. Difficulty sleeping | <input type="checkbox"/> | 47 |
| 30. Demands a lot of attention | <input type="checkbox"/> | 48 |
| 31. Often impatient | <input type="checkbox"/> | 49 |
| 32. Irritable | <input type="checkbox"/> | 50 |
| 33. Easily angered | <input type="checkbox"/> | 51 |
| 34. Threats/gestures of violence | <input type="checkbox"/> | 52 |
| 35. Physically violent | <input type="checkbox"/> | 53 |
| 36. Very easily affected by alcohol | <input type="checkbox"/> | 54 |

37. Did he drink before the accident?

☐ 55

- 0 = Abstained
- 1 = Occasionally
- 2 = Social
- 3 = Heavy
- 4 = Alcoholic

38. Had there been any trouble with the police at any time before the injury?

☐ 56

- 0 = No
- 1 = Yes (specify)

39. Since the accident, has there been any trouble with the police?

☐ 57

- 0 = No
- 1 = Yes (specify)

AS A RESULT OF THE INJURY, DO ANY OF THE FOLLOWING APPLY TO THE PATIENT OVER THE LAST YEAR?

- 0 = Absent
- 1 = Present

40. Upset by changes in routine

☐ 58

41. Suspicious/Mistrustful of people

☐ 59

42. Tries to tell people what to do

☐ 60

43. Nosy or interfering

☐ 61

44. Behaving Oddly/Expressing odd ideas

☐ 62

45. Difficulty in speaking
(dysarthria or slurred speaking)

☐ 63

AS A RESULT OF INJURY, DO ANY OF THE FOLLOWING APPLY
TO THE PATIENT OVER THE LAST YEAR?

Column
(Card)

0 = Absent
1 = Present

- | | |
|---|-----------------------------|
| 46. Difficulty in expressing himself
(Dysphasia) | <input type="checkbox"/> 64 |
| 47. Difficulty in holding a conversation | <input type="checkbox"/> 65 |
| 48. Difficulty in understanding speech | <input type="checkbox"/> 66 |
| 49. Difficulty in following a
conversation | <input type="checkbox"/> 67 |
| 50. Difficulty with memory | <input type="checkbox"/> 68 |

N.B. ADMINISTER MEMORY CHECK LIST AT THIS POINT

- | | |
|---|-----------------------------|
| 51. Difficulty in concentrating | <input type="checkbox"/> 69 |
| 52. Talking too much | <input type="checkbox"/> 70 |
| 53. Difficulty in behaving properly
in Company | <input type="checkbox"/> 71 |
| 54. Withdrawn in Company | <input type="checkbox"/> 72 |
| 55. Avoiding Company | <input type="checkbox"/> 73 |
| 56. Change in sex life | <input type="checkbox"/> 74 |
| 57. Change in sex attitudes
(Patient) | <input type="checkbox"/> 75 |
| (Informant) | <input type="checkbox"/> 76 |
| 58. Change in sex capabilities | <input type="checkbox"/> 77 |
| N.B. (Go back to question 5) | |
| 59. Difficulty in washing (ADL) | <input type="checkbox"/> 78 |

0 = Absent
1 = Present

Colu
(Car

- | | | |
|---|--------------------------|----|
| 60. Less concern about being clean and tidy | <input type="checkbox"/> | 7 |
| 61. Bed wetting or wetting himself at other times | <input type="checkbox"/> | 8 |
| | <input type="checkbox"/> | |
| | <input type="checkbox"/> | |
| | <input type="checkbox"/> | |
| | subnum | ca |
| 62. Clumsiness/Bumping into things | <input type="checkbox"/> | 9 |
| 63. Needs someone to stay in house to look after him | <input type="checkbox"/> | 10 |
| 64. Cannot look after household (someone else has to do it) | <input type="checkbox"/> | 11 |
| 65. Cannot go out without someone to look after him | <input type="checkbox"/> | 12 |
| 66. Loss of interest | <input type="checkbox"/> | 13 |
| 67. Childish behaviour | <input type="checkbox"/> | 14 |
| 68. Rapid mood changes | <input type="checkbox"/> | 15 |
| 69. Depression | <input type="checkbox"/> | 16 |
| 70. Worry about the future | <input type="checkbox"/> | 17 |
| 71. Talk of suicide | <input type="checkbox"/> | 18 |
| 72. Attempted suicide | <input type="checkbox"/> | 19 |
| 73. Personality change | <input type="checkbox"/> | 20 |
| 74. Refuses to admit to problems | <input type="checkbox"/> | 21 |

Column
(Case)

75. Do YOU feel able to cope?

☐ 21

- 0 = No help needed
- 1 = Some help needed
- 2 = Feels patient needs relief hospitalisation
- 3 = Feels patient needs permanent hospitalisation

76. Are you still able to confide in your husband about problems?

☐ 23

- 0 = Not at all
- 1 = To a limited extent
- 2 = Yes fully

77. Is there anyone (else) you can talk to?

☐ 24

- 0 = Never
- 1 = Only sometimes
- 2 = Yes - when needed

If so, how often do you talk to them?

☐ 25

- 0 = Very occasionally
- 1 = At least once a month
- 2 = At least once a week

If so, who is it?

☐ 26

- 0 = Friend/Neighbour
- 1 = Relative

78. Overall - How much strain/distress have you felt because of the changes in your husband/wife since the accident

☐ 27

7	6	5	4	3	2	1
Severe Strain			Moderate Strain	No strain		

(Code 6)

Column
(Card)

79. Which changes have been most distressing for you?

- | | | | |
|--|--------|---|-----------|
| 00 = Physical incapacity | First | <input type="checkbox"/> <input type="checkbox"/> | 28-29 (2) |
| 01 = Sight/hearing | | | |
| 02 = Enuresis | Second | <input type="checkbox"/> <input type="checkbox"/> | 30-31 |
| 03 = Other Physical Difficulty | | | |
| 04 = Anxiety/depression | Third | <input type="checkbox"/> <input type="checkbox"/> | 32-33 |
| 05 = Rapid mood swings | | | |
| 06 = Tempers/arguments/irritability | | | |
| 07 = Demanding attention/impatience | | | |
| 08 = "Childish behaviour" | | | |
| 09 = "Changed personality" | | | |
| 10 = Other emotional difficulties | | | |
| 11 = Poor memory | | | |
| 12 = Language difficulty (expression and/or comprehension) | | | |
| 13 = Poor concentration | | | |
| 14 = "Decline in mental powers" generally | | | |
| 15 = Other cognitive difficulty | | | |
| 16 = Often feeling unwell | | | |
| 17 = Restlessness | | | |
| 18 = Loss of interest/apathy | | | |
| 19 = Intolerance of noise | | | |
| 20 = Complaining a lot about difficulties | | | |
| 21 = Social withdrawal/causing social embarrassment | | | |
| 22 = Other behavioural problem | | | |
| 23 = Sensitivity to alcohol and alcohol problems | | | |
| 24 = Fits and seizures | | | |
| 25 = Role Shift | | | |
| 26 = Rigidity (In thinking) | | | |

22 = ANY OTHER RESPONSES

STAD INQUIRY FOLLOW UP STUDY

Column
(Card)

Name:

Date:

EFFECTS ON THE HOUSEHOLD

TYPE 1 BURDEN

1. Are there any housing problems at present? (eg dampness, bad area, wanting to move)

0 = No
1 = Yes

☐ 34(2)

2. How many rooms are there in the house?

Obtain details - No of public and bedrooms

☐ 35-3

3. Is the entrance to the house on the ground floor?

0 = Yes (no steps, or with ramp)

☐ 37

1 = Yes (with steps)

2 = No (1 up)

3 = No (2 + up with lift)

4 = No (2 + up no lift)

4. Are there any stairs in the house?

0 = No
1 = Yes

☐ 38

5. Is the house rented or bought? (ie tenure of dwelling)

0 = Owner Occupier
1 = Rented (council)
2 = All other tenure

☐ 39

6. Does your house present any problems for your H/W? (eg lack of space, WC, stairs) (If so specify)

0 = No problems
1 = Moderate problems
2 = Severe problems

☐ 40

7. Are there any alterations needed to the home, (or have they been done), because of your H/I's injury? (If so, specify)

(Card)

0 = No
1 = Yes, alterations made
2 = Yes, alterations needed

☐ 41

8. Who lives in the household? (list with ages and relationship to patient)

9. No of persons in household (including patient)

☐ 42

10. No of persons aged 0 - 4

☐ 44

11. No of persons aged 5 - 10

☐ 45

12. No of persons aged 11 - 16

☐ 46

13. No of persons aged 17 +

☐ 47

14. Patient lives (with)

14. Alone

0 = No
1 = Yes

☐ 48

15. Spouse

0 = No
1 = Yes

☐ 49

16. Children

0 = No
1 = Yes

☐ 50

17. Parent (s)

0 = No
1 = Yes

☐ 51

Column

C. Lunn
(Card)

18. Parent (s)-in-law

0 = No
1 = Yes☐ 52

19. Other relatives

0 = No
1 = Yes☐ 53

20. Non-relatives

0 = No
1 = Yes☐ 54

21. Do you think the house is overcrowded?

0 = No
1 = Yes☐ 55

22. How often does the patient see his own doctor (GP)?

- 0 = Irregular contact
- 1 = Regular contact, not head injury related
- 2 = Regular head injury contact - report prescriptions or sick leave only
- 3 = Regular head injury contact - consultations
- 4 = Regular statutory examination or invalidity benefit

☐ 56

(code highest number which applies)

23. Do you feel that the help given by his GP has been adequate?

0 = Yes
1 = No☐ 57

Comments:

Column
(Card)

24. Has the patient been getting any other help since his injury?

0 = No

1 = Yes

Occupational Therapy	<input type="checkbox"/>	5
Physiotherapy	<input type="checkbox"/>	5
Speech Therapy	<input type="checkbox"/>	6
Psychology	<input type="checkbox"/>	6
Psychiatry	<input type="checkbox"/>	6
Social Work	<input type="checkbox"/>	6
E.R.C.	<input type="checkbox"/>	6
District	<input type="checkbox"/>	6
Other (specify)	<input type="checkbox"/>	6

25. If yes to question 24, when did he receive this help?

1 = Up to 1 week

2 = > 1 week - 1 month

3 = > 1 month - 3 months

4 = > 3 months - 6 months

5 = > 6 months - 1 year

6 = > 1 year

Occupational Therapy	<input type="checkbox"/>	6
Physiotherapy	<input type="checkbox"/>	6
Speech Therapy	<input type="checkbox"/>	6
Psychology	<input type="checkbox"/>	7
Psychiatry	<input type="checkbox"/>	7
Social Work	<input type="checkbox"/>	7
E.R.C.	<input type="checkbox"/>	7
District	<input type="checkbox"/>	7
Other (specify)	<input type="checkbox"/>	7

26. For how long did you receive this help?

1 = < 1 week

2 = > 1 week - 1 month

3 = > 1 month - 3 months

4 = > 3 months - 6 months

5 = > 6 months - 1 year

6 = > 1 year

Occupational Therapy	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>
Speech Therapy	<input type="checkbox"/>
Psychology	<input type="checkbox"/>

26/

Psychiatry

☐ Colum
(Car)

Social Work

☐

E.R.C.

☐

District

☐

Other (specify)

☐

27. Did you feel that the help he received was adequate?

0 = Adequate
1 = Inadequate

Occupational Therapy

☐

Physiotherapy

☐

Speech Therapy

☐

Psychology

☐

Psychiatry

☐

Social Work

☐

E.R.C.

☐

District

☐

Other (specify)

☐28. During the week before the injury, was your husband/
wife working

0 = Overtime
1 = Full Time
2 = Part Time
3 = Off work (job open)
4 = Unemployed (less than 6 months)
5 = Unemployed (more than 6 months)
6 = Retired
7 = Housewife

☐

2

29. During the week prior to this interview, was your
husband/wife working

0 = Overtime
1 = Full Time/

☐

2

Column
(Card)

- 2 = Part Time
- 3 = Off work (job open)
- 4 = Unemployed (less than 6 months)
- 5 = Unemployed (more than 6 months)
- 6 = Retired
- 7 = Housewife

30. Before the injury, how often was your H/W absent from work?

- 0 = Seldom
- 1 = Occasionally
- 2 = Frequently

☐ 21

31. In the last year, how often has your H/W been absent from work?

- 0 = Seldom
- 1 = Occasionally
- 2 = Frequently
- 3 = Permanently

☐ 25

32. Before the injury, was he in regular work?

- 0 = Yes
- 1 = No

☐ 26

33. In the last year, has he been in regular work

- 0 = Yes
- 1 = No

☐ 27

34. If working, is his present job as difficult as the job he had before?

- 0 = More difficult
- 1 = Similar/same
- 2 = Less difficult

☐ 28

35. If working, is he working for the same employer as before the accident?

- 0 = same
- 1 = different

☐ 29

Column
(Card)

36. How well do you think your H/W is coping with the work he is doing at present? (Probe and specify)

- 0 = No difficulty
1 = Some difficulty
2 = Considerable difficulty

☐ 30

37. Has his future work capacity been adversely affected by the injury? (Probe and specify)

- 0 = Not affected
1 = Mild/Moderate
2 = Severe

☐ 31

38. If housewife - Before the injury, how did she manage with the housework?

- 0 = No difficulty
1 = Some difficulty (specify)
2 = Considerable difficulty (specify)

☐ 32

39. In the last year, how has she managed with the housework?

- 0 = No difficulty
1 = Some difficulty (specify)
2 = Considerable difficulty (specify)

☐ 33

40. Are there any financial problems at present?

- 0 = None
1 = Minor ("struggle")
2 = Major (threat of legal action)

☐ 34

41. Did you have any financial problems just before the injury?

- 0 = None
1 = Minor (struggle)
2 = Major (threat of legal action)

☐ 35

Colu
(Car

42. Is your W/W a main earner or contributor to the family income at the present time?
(Patient's current financial status)

☐

0 = Only wage earner
1 = Chief wage earner
2 = Contributory wage earner
3 = Self supporting
4 = Statutory beneficiary
5 = Dependent financially
6 = Other (specify)

43. Is the patient wholly or partly supported by income from compensation?

☐

0 = Not at all
1 = Partly maintained
2 = Wholly maintained

44. What was the amount of compensation obtained
thousands of pounds

45. What is the income generated by this?

thousands of pounds
per annum

46. Before the accident, was your H/W a main earner or contributor to the family income? (Patient's pre injury financial status)

☐

0 = Only wage earner
1 = Chief wage earner
2 = Contributory wage earner
3 = Self supporting
4 = Statutory beneficiary
5 = Dependent financially
6 = Other (specify)

47. What effect has the accident had on the family's
NET income? (Take home pay)

☐

0 = Little or none
1 = Some
2 = Considerable

Column
(Card)

39. Was any additional expenditure resulted from caring for the husband/wife, or from the husband/wife staying at home? (List and specify)

☐

45

0 = No
1 = Yes

40. In the last year has anyone in the household had to stay away from work to look after your W/?
(If yes, specify)

☐

46

0 = No
1 = Yes, occasionally
2 = Yes, 13 days +
3 = Yes, permanently

50. In the last year has anyone in the household had to stay away from school to look after your W/?
(If yes, specify)

☐

47

0 = No
1 = Yes, occasionally
2 = Yes, 13 days +
3 = Yes, permanently

51. In the last year has your household routine been upset since your W/? injury?

☐

48

0 = No
1 = Yes

Column
(Card)

52. Has the patient changed his leisure activities since the injury?

0 = No
1 = Yes

49(

If so, is this because of

0 = No
1 = Yes

financial restraints

☐

50

Physical handicap

☐

51

Social withdrawal

☐

52

Loss of interest

☐

53

Loss of friends

☐

54

Other (specify)

☐

55

53. Have YOU changed your leisure activities since the injury?

0 = No
1 = Yes

☐

56

If so, is this because of

0 = No
1 = Yes

Financial restraints

☐

57

Patient's physical state

☐

58

Patient's emotional/
behavioural state☐

59

Patient's need for
supervision☐

60

Other (specify)

☐

61

54. How often do You see your own doctor (GP)?

0 = Irregular Contact
1 = Regular Contact

☐ 6

If regular contact, probe for specific reason and specify

55. In your opinion what effect has the accident had on the family unit?

No effect

☐ 63

Some effect (specify)

☐ 64

Major effect (specify)

☐ 65

Column
(Card)

Patient's Name _____ Date _____

Code L-5
1-5

	PATIENT as he/she was BEFORE INJURY											
1	Talkative	—	—	—	—	—	—	—	—	—	quiet	<input type="checkbox"/> 10
2	even-tempered	—	—	—	—	—	—	—	—	—	quick tempered	<input type="checkbox"/> 11
3	relies on others	—	—	—	—	—	—	—	—	—	does things himself	<input type="checkbox"/> 12
4	affectionate	—	—	—	—	—	—	—	—	—	cold	<input type="checkbox"/> 13
5	fond of company	—	—	—	—	—	—	—	—	—	dislikes company	<input type="checkbox"/> 14
6	irritable	—	—	—	—	—	—	—	—	—	easy-going	<input type="checkbox"/> 15
7	unhappy	—	—	—	—	—	—	—	—	—	happy	<input type="checkbox"/> 16
8	excitable	—	—	—	—	—	—	—	—	—	calm	<input type="checkbox"/> 17
9	energetic	—	—	—	—	—	—	—	—	—	lifeless	<input type="checkbox"/> 18
10	down to earth	—	—	—	—	—	—	—	—	—	out of touch	<input type="checkbox"/> 19
11	rash	—	—	—	—	—	—	—	—	—	cautious	<input type="checkbox"/> 20
12	listless	—	—	—	—	—	—	—	—	—	enthusiastic	<input type="checkbox"/> 21
13	mature	—	—	—	—	—	—	—	—	—	childish	<input type="checkbox"/> 22
14	sensitive	—	—	—	—	—	—	—	—	—	insensitive	<input type="checkbox"/> 23
15	cruel	—	—	—	—	—	—	—	—	—	kind	<input type="checkbox"/> 24
16	generous	—	—	—	—	—	—	—	—	—	mean	<input type="checkbox"/> 25
17	unreasonable	—	—	—	—	—	—	—	—	—	reasonable	<input type="checkbox"/> 26
18	stable	—	—	—	—	—	—	—	—	—	changeable	<input type="checkbox"/> 27

Column
(Card)

Patient's Name _____ Date _____

	PATIENT as he/she is NOW						Code I 1-5
1	Talkative	—	—	—	—	quiet	<input type="checkbox"/> 90
2	even-tempered	—	—	—	—	quick tempered	<input type="checkbox"/> 10
3	relies on others	—	—	—	—	does things himself	<input type="checkbox"/> 11
4	affectionate	—	—	—	—	cold	<input type="checkbox"/> 12
5	fond of company	—	—	—	—	dislikes company	<input type="checkbox"/> 13
6	irritable	—	—	—	—	easy-going	<input type="checkbox"/> 14
7	unhappy	—	—	—	—	happy	<input type="checkbox"/> 15
8	excitable	—	—	—	—	calm	<input type="checkbox"/> 16
9	energetic	—	—	—	—	lifeless	<input type="checkbox"/> 17
10	down to earth	—	—	—	—	out of touch	<input type="checkbox"/> 18
11	rash	—	—	—	—	cautious	<input type="checkbox"/> 19
12	listless	—	—	—	—	enthusiastic	<input type="checkbox"/> 20
13	mature	—	—	—	—	childish	<input type="checkbox"/> 21
14	sensitive	—	—	—	—	insensitive	<input type="checkbox"/> 22
15	cruel	—	—	—	—	kind	<input type="checkbox"/> 23
16	generous	—	—	—	—	mean	<input type="checkbox"/> 24
17	unreasonable	—	—	—	—	reasonable	<input type="checkbox"/> 25
18	stable	—	—	—	—	changeable	<input type="checkbox"/> 26

Column
(Card)

HEAD INJURY FOLLOW-UP STUDY

Name:

Date:

Subnum

Card

Type

1. What is the last thing you remember before your accident?

Duration of Retrograde Amnesia

days

9

(if less than 1 day, code in hours)

hours

11

mins

13

2. What is the first thing you remember after the accident?

Duration of Amnesia after injury

days

15

Time from injury to onset of main period of amnesia

1 = Nil

2 = Up to 1 hour

3 = 1 hour - 1 day

4 = More than 1 day

18

3. Are you right or left handed?

0 = R handed

1 = L handed

2 = Ambidextrous

19

If left handed

0 = Twisted

1 = Conventional

2 = No set pattern

20

4. Have you always been handed?

0 = No change
1 = Change

5. Did you have any other head injuries?

Give number of PREVIOUS head injuries
which led to hospital admission

Give number of SUBSEQUENT head injuries
which led to hospital admission

6. Have you had any (other) serious illness?
(eg infections, heart/chest complaints, strokes, epilepsy)

PRIOR to injury 0 = None
 5 = Non CNS illness
 6 = CNS illness
 7 = Both

SUBSEQUENT to injury 0 = None
 5 = Non CNS illness
 6 = CNS illness
 7 = Both

7. Are you taking any medicines at present?

1 = No
2 = Yes

Anticonvulsants

Major tranquilisers

Anxiolytics

Sleepers (hypnotics)

Barbiturates

Antidepressants

Anaesthetics

Other

2

2

2

2

3

3

3

3

Column
(card)

How often do you see your own doctor (GP)?

- 0 = Irregular contact
 1 = Regular contact, not head injury related
 2 = Regular head injury contact - repeat prescriptions only
 3 = Regular head injury contact - consultations

☐ 34(1)

Do you feel that the help given by your GP has been adequate?

- 0 = Yes
 1 = No

☐ 35

Comments:

Have you been getting any other help since the injury?

- 0 = No
 1 = Yes

Occupational Therapy

☐ 36

Physiotherapy

☐ 37

Speech Therapy

☐ 38

Psychology

☐ 39

Psychiatry

☐ 40

Social Work

☐ 41

F.R.C.

☐ 42

District

☐ 43

Other (specify)

☐ 44

Column
(Card)

. If yes to question 10, when did you receive this help?

1 = Up to 1 week	Occupational Therapy	<input type="checkbox"/>	45(1)
2 = > 1 week - 1 month	Physiotherapy	<input type="checkbox"/>	46
3 = > 1 month - 3 months	Speech Therapy	<input type="checkbox"/>	47
4 = > 3 months - 6 months	Psychology	<input type="checkbox"/>	48
5 = > 6 months - 1 year	Psychiatry	<input type="checkbox"/>	49
6 = > 1 year	Social work	<input type="checkbox"/>	50
	E.R.C.	<input type="checkbox"/>	51
	District	<input type="checkbox"/>	52
	Other (specify)	<input type="checkbox"/>	53

. For how long did you receive this help?

1 = Up to 1 week	Occupational Therapist	<input type="checkbox"/>	54
2 = > 1 week - 1 month	Physiotherapy	<input type="checkbox"/>	55
3 = > 1 month - 3 months	Speech Therapy	<input type="checkbox"/>	56
4 = > 3 months - 6 months	Psychology	<input type="checkbox"/>	57
5 = > 6 months - 1 year	Psychiatry	<input type="checkbox"/>	58
6 = > 1 year	Social Work	<input type="checkbox"/>	59
	E.R.C.	<input type="checkbox"/>	60
	District	<input type="checkbox"/>	61
	Other (specify)	<input type="checkbox"/>	62

Column
(Card)

Did you feel that the help you received was adequate?

0 = Adequate
1 = Inadequate

Occupational Therapy	<input type="checkbox"/>	630
Physiotherapy	<input type="checkbox"/>	64
Speech Therapy	<input type="checkbox"/>	65
Psychology	<input type="checkbox"/>	66
Psychiatry	<input type="checkbox"/>	67
Social Work	<input type="checkbox"/>	68
E.R.C.	<input type="checkbox"/>	69
District	<input type="checkbox"/>	70
Other (specify)	<input type="checkbox"/>	71

4. Comments on help received:

CURRENT PROBLEMS

DO YOU HAVE ANY TROUBLE (WITH YOUR).....

Code changes subsequent to injury

= No
= Yes

15. Memory	<input type="checkbox"/>	72
16. Concentration (eg reading, T.V.)	<input type="checkbox"/>	73
17. Moving (eg arms, legs, neck, back)	<input type="checkbox"/>	74
18. Sight	<input type="checkbox"/>	75
19. Hearing	<input type="checkbox"/>	76
20. Taste	<input type="checkbox"/>	76
21. Smell	<input type="checkbox"/>	77
22. Speaking or finding the right word	<input type="checkbox"/>	78

Colu
(Car)0 = No
1 = Yes

23. Understanding what people say to you

subnum cc

24. Headaches

HAS THERE BEEN A

25. Change in your sex life

26. Change in sex attitudes

27. Change in sex capabilities

DO YOU EASILY GET

28. Depressed

29. Irritable

30. Angry

31. Violent

32. Tired

33. Anxious

DO YOU HAVE.....

34. Blank spells when you are not aware of
things around you

35. Fits

36. Dizzy spells

37. How do you get on with people in Company?
Worse than before38. Do you have the same friends you had before
the injury?

= No
= Yes

Column
(Card)

WORK

39. Were you employed at the time of the accident?

☐ 2

If so, what was your job?

☐ 2

40. Are you working now?

☐ 26

41. Are you fit for your old job?

☐ 27

42. Do you hope to start work again?

☐ 28

If so, at your old job, similar type of work,
or will it need to be something less demanding?

ORIENTATION

- | | |
|------------------|----------|
| 1. Name | 6. Year |
| 2. Age | 7. Month |
| 3. Date of Birth | 8. Date |
| 4. Address | 9. Day |

5. Where are you now?

a) Hospital

b) City

Total Score

(Max 10)

29-3

APPENDIX DDETAILED QUESTIONNAIRE DATA

The data presented in this appendix are the full results from the closed items of the questionnaire. The presentation is in the form of Tables 1 to 7. These record frequency distributions and occasional measures of central tendency. The format follows that of the questionnaire itself, and there is similar division into sub-sections. Where fully or partially open-ended items called for description from respondents, this is noted in the tables. The descriptive results are contained in Chapter 6 (sections 1 and 2).

Table 1	Historical
Table 2	Informant
Table 3	Accident
Table 4	Post-accident
Table 5	Agencies
Table 6	Carer
Table 7	Family occupation/s, income and life style

TABLE 1 (Frequency distributions)

HISTORICAL1.1 Ages at time of injury (Q.1-2)

11-15	16-20	21-25	26-30	31-35	36-40	41-45
1	2	4	-	2	-	2

1.2 Sex (Q.3)

Males	Females	Total
9	2	11

1.3 Marital status at time of injury (Q.4)

Single	Married	Separated/divorced	Child
5	3	2	1

1.4 Length of hospitalisation (Q.5)

3 - 6 mths	7 - 10 mths	11 - 14 mths
7	3	1

1.5 Diagnosis of severity of injury (Q.6-7)

Severe (PTA <4wks)	Very Severe (PTA 4-8wks)	Extremely severe (PTA >8wks)
3	3	5

1.6 Pre-accident disability (Q.8)

None	Previous episodes of concussion	Stroke as young child
7	3	1

1.7 Education (Q.9)

Form 3 (plus trade cert.)	Form 5	S.C.	U.E.	Intermed. Pupil	Not known
1	6	1	1	1	1

TABLE 1 (continued)1.8 Occupation (Q.10)

Student	Farming and Horticulture	Skilled Trades	Supervisory (manual)	Clerical	Factory Work (unskilled)
---------	-----------------------------	-------------------	-------------------------	----------	--------------------------------

1	4	1	3	1	1
---	---	---	---	---	---

1.9 Drug/alcohol use before accident (Q.11-12)

Social drinking	No alcohol
-----------------	------------

10	1
----	---

Occasional Cannabis	Asthma Medication	No drugs
---------------------	-------------------	----------

1	1	9
---	---	---

1.10 Police involvement before the accident (Q.13)

Yes	No
-----	----

-	11
---	----

TABLE 2 (Frequency distributions)INFORMANT2.1 Relationship to patient (Q.14-16)

Parent/s	Spouse	Companion
7	3	1

Ages:

Parent/s	Spouse	Companion
46-65	33-45	53

Length of relationship:

Parent/s	Spouse	Companion
Life	2-22yrs	3yrs

2.2 Main responsibility for caring for patient (Q.17)

Independent living	With parent/s	With spouse	Institution care	Shared living with companion
3	4	2	1	1

* Q.18 - Those living in household - descriptive (refer discussion)

TABLE 3 (Frequency distributions)**ACCIDENT**3.1 **How injured** (Q.19-20)

MVA * Driver	MVA Pedestrian	MVA Cyclist/motor-cyclist	Fell	Injured by horse
4	2	2	1	2

* motor vehicle accident

(plus description - refer case studies section)

3.2 **Gulpability** (Q.21)

Uncertain	Other's	Completely accidental
5	3	3

3.3 **Alcohol/drugs at time of accident** (Q.22-23)

No alcohol	Some alcohol	Not known
8	2	1
No drugs	Asthma medication	Not known
8	1	2

TABLE 4 (Frequency distributions)**POST-ACCIDENT****4.1 Able to get about?** (Q.24)

Independent	Wheelchair	Uses walking stick
7	3	1

4.2 Assistance/supervision needs (Q.25)

Wholly independent	Wheelchair	Needs supervision
6	3	2

4.3 Physical problems over past year (Q.26)

	<u>Ranked order</u> (n)
Sight	8
Balance	7
Headaches	6
Speech	5
Arm weakness	5
Smell	4
Hemiplegia	3
Leg weakness	3
Taste	3
Seizures	3
Tetraplegia	2
Gait	2
Dizzy spells	2
Choking episodes	2
Hearing	1
Incontinence	1
Saliva problems	1
Paraplegia	-

TABLE 4 (continued)**4.4 Moods and behaviour over past year (Q.27)**

	<u>Ranked mean direction</u> <u>of change</u>	<u>Number</u>	
Sexual activity	- 6.7	4	*
Decision making	- 6.0	1	*
Communication/conversation	- 5.2	11	
Energy level	- 4.9	10	
Concentration	- 4.5	11	
Responsibility	- 4.2	10	
Memory	- 4.3	10	
Independence	- 4.3	11	
Judgement	- 4.0	10	
Inappropriate laughter	+ 4.0	2	*
Motivation	- 4.0	1	*
Sleeping patterns	- 3.4	10	
Self-control	- 3.2	10	
Aggression	+ 2.8	6	
Patience	- 2.6	11	
Tolerance	- 2.5	11	
Interaction with others	- 2.5	11	
Depression	+ 2.4	10	
Self-esteem	- 2.4	11	
Anxiety	+ 2.1	10	
Personal habits/daily routines	- 1.8	10	
Co-operation	- 1.5	10	
Insight	- 1.5	11	
Anger and frustration	+ 1.5	4	*
Eating/drinking patterns	1.4	11	

* denotes half or less of the sample

4.5 Patient been involved with police since the accident?
(Q.28)

No	Yes
9	2

TABLE 5 (Frequency distributions)**AGENCIES****5.1 How often patient sees GP (Q.29)**

Irregular contact	Regular head injury consultations	Medical certificates only	Repeat prescriptions only
4	2	3	2

5.2 Quality of help/support given since hospital discharge (Q.30-31)

	Rating (10-point scale)	Number
GP	7.3	9
Rehab. Unit Doctors	7.1	10
Specialist	6.8	11
Occupational therapist	7.9	8
Physiotherapist	6.5	6
Speech therapist	7.0	5 *
Psychological assessment	6.1	9
Psychological counselling	7.3	3 *
Hospital social worker	7.0	7
District nurse	7.0	5 *
Sheltered workshop or Day care centre	8.7	4 *
ACC Rehab. Co-ordinator	7.1	10
DSW social worker	10.0	1 *
Home help	5.3	3 *
Child care	8.0	1 *
Other:		
IHC	7.0	1 *
Attendant care	8.7	3 *

* denotes half or less of the sample

5.3 Length of assistance after hospital discharge (Q.32)

	Not Rec'd	1-6 mths	7-12 mths	13-24 mths	25+ mths	Ongoing
Rehab. Unit Doctors	1	2	2	2	-	4
Specialist	1	1	1	1	-	7
Occupational therapist	4	1	1	1	-	4
Physiotherapist	5	1	2	1	-	2
Speech therapist	6	-	2	1	-	2
Psychological assess.	2	4	1	1	-	3
Psychological couns.	8	-	1	-	-	2
Hospital social worker	6	2	1	-	1	1
District nurse	6	3	1	-	-	1
Sheltered workshop or Day care centre	7	1	-	-	-	3
ACC Rehab. Co-ordinator	1	1	-	2	2	5
DSW social worker	10	-	-	1	-	-
Home help	8	-	-	1	-	2
Child care	10	-	-	1	-	-
IHC	10	-	-	-	-	1
Attendant care	5	-	-	-	-	4

TABLE 5 (continued)5.4 Housing alterations (Q.33)

Done	Not needed	Handrails only
5	4	2

range of costs (excluding handrails): \$300 - \$91,000

5.5 Equipment provided (Q.34)

Yes	Not needed	Sufficient for needs?
9	2	Yes (all cases)

5.6 Paid home help (Q.35-36)

Yes	No
2	9

(20 hours per week each - costs met by ACC in both cases)

5.7 Unpaid home help (Q.37-38)

Yes	No
-	11

5.8 Attendant care (Q.39-40)

Yes	No
4	7

(ranges from 14 hrs per week to full-time care - costs met by ACC in all four cases)

5.9 Source of attendant care (Q.41)

Agency/ Institution	Private	Parents	N/A
2	1	1	7

5.10 Sufficient for needs? (Q.42)

Yes (all four cases)

TABLE 6 (Frequency distributions)**CAREER****6.1 Able to confide in patient about problems?** (Q.43)

Limited	Fully	Not at all
4	6	1

6.2 Anyone else you can talk to? (Q.44)

Yes	Only sometimes
9	2

How often:

Weekly	Monthly	Occasionally
2	1	8

Who is it:

Relative	Friend
8	3

6.3 Do you have as many friends as you did before the patient's injury? (Q.45)

Close friends:

Distant friends:

Same	Increased	Decreased	Same	Increased	Decreased
7	1	3	3	3	5

6.4 How often do YOU see your GP (Q. 46)

Irregular contact	Regular contact
8	3

Reason for regular contact:

Medical condition aggravated by stress	Stress	N/A
2	1	8

TABLE 6 (continued)

6.5 Have you received (or are you receiving) sufficient help and support from the following agencies/people?
(Q.47)

	Not Rec'd	Yes	No
GP	2	8	1
Specialist	1	5	5
Rehab. Unit	-	9	2
Information about head injury	-	4	7
Support group	5	6	-
Day-care centre	9	1	1
Sheltered workshop or activities centre	7	3	1
Para-medical services	-	9	2
Professional counselling			
- patient	8	3	-
Professional counselling			
- yourself	10	-	1
Someone to confide in	-	9	2
Church/minister	3	6	2
Organised social outings	6	4	1
District nursing	6	5	-
Hospital social worker	3	7	1
ACC Rehab. Co-ordinator	1	6	4
DSW social worker	10	1	-
Home help	8	2	1
Child care	10	-	1
Attendant care	7	4	-
Relief care (annually)	8	2	1
Family support - in house:			
Spouse (not patient)	5	6	-
Parents	11	-	-
Children	7	4	-
Brothers/sisters	11	-	-
In-laws	10	1	-
Family support - away:			
Spouse	11	-	-
Parents	6	5	-
Children	1	10	-
Brothers/sisters	3	7	1
In-laws	6	4	1
Friends	-	9	2
Neighbours	1	8	2
Financial assistance	-	7	4
IHC	10	1	-

6.6 Is patient the same person you knew before the injury? (Q.48)

Major change	Some change
4	7

plus description (refer case studies section)

* Q. 49 - the most distressing changes - descriptive
(refer case studies section)

TABLE 6 (continued)

6.7 Overall, how much strain/distress have you felt
because of these changes? (Q.50) felt

	0	1	2	3	4	5	6	7	8	9	10
Low											Extreme

	-	-	-	-	-	2	-	2	2	-	5
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* Q. 51 - future changes - descriptive (refer case studies section)

* Q.52 - concerns about possible future changes -
 (refer case studies section)

TABLE 7 (Frequency distributions)

FAMILY OCCUPATION/S, INCOME AND LIFE STYLE7.1 Was the patient working during the week before the injury? (Q. 53)

Full-time	Student
10	1

7.2 During the week prior to the interview, was the patient working? (Q.54)

Full-time	Part-time	Not worked since injury	Supervised light work	Formerly student
4	1	4	1	1

7.3 Before the injury, how often was the patient absent from work? (Q.55)

Seldom	Occasionally	Student
9	1	1

7.4 In the last year, how often has the patient been absent from work? (Q.56)

Seldom	Occasionally	Frequently	Permanently	Formerly student
3	1	2	4	1

7.5 Before the injury, was the patient in regular work? (Q.57)

Yes	Student
10	1

7.6 In the last year, has the patient been in regular work? (Q.58)

Yes	No	Formerly student
3	7	1

7.7 If working, is the job as difficult as the pre-injury job? (Q. 59)

Similar/same	Less difficult	N/A
1	5	5

7.8 If working, is it for the same employer? (Q. 60)

Same	Self-employed (same)	Different	N/A
1	2	3	5

TABLE 7 (continued)

7.9 How well is the patient coping with the present work? (Q. 61)

No difficulty	Some difficulty	N/A
2	4	5

7.10 Has future work capacity been adversely affected? (Q. 62)

Moderately	Severely
2	9

* Q. 63 - 64 - Housewife - not represented in sample

7.11 If student, how did he/she perform at school before injury? (Q. 65)

No difficulty	N/A
1	10

7.12 In the last year, how has he/she performed at school? (Q. 66)

Unable to attend	N/A
1	10

7.13 Financial problems at present? (Q. 67)

None	Major	Minor
6	1	4

7.14 Financial problems just before the injury? (Q. 68)

None
11

7.15 Patient main earner/contributor to family income at present? (Q. 69)

Self-supporting	Beneficiary	Partly self-supporting
2	8	1

7.16 Patient wholly/partly supported by income from ACC/DSW? (Q. 70)

Not at all	Wholly ACC	Partly ACC	Wholly DSW	Partly DSW
2	5	2	1	1

TABLE 7 (continued)

7.17	<u>Before the injury, was the patient a main earner/contributor to the family income?</u> (Q.71)			
	Self supporting	Contributor	Chief earner	Dependent financially (student)
	6	1	3	1
7.18	<u>Effect of injury on family's net income?</u> (Q. 72)			
	Little or none	Some	Considerable	
	5	3	3	
7.19	<u>Did informant work in an occupation pre-injury?</u> (Q. 73)			
	No	Yes, full-time	Yes, part-time	
	6	3	2	
7.20	<u>This employment given up to care for patient?</u> (Q.74)			
	Yes	No	Reduced hours	N/A
	3	1	1	6
7.21	<u>Taken up employment since the accident?</u> (Q. 75)			
	Yes	No	Already working	
	2 (for financial reasons)	7	2	
7.22	<u>Additional expenditure incurred from caring for patient, or patient staying at home?</u> (Q. 76)			
	Yes	No		
	10	1		
	(plus description - refer case studies section)			
7.23	<u>Patient changed leisure activities since the injury?</u> (Q. 77)			
	Yes	No		
	11	-		
	(plus description - refer case studies section)			
7.24	<u>Informant changed leisure activities since the injury?</u> (Q.78)			
	Yes	No		
	7	4		
	(plus description - refer case studies section)			

TABLE 7 (continued)

7.25 Anyone in household had to stay away from
work/school to look after patient? (Q. 79)

Yes	No
-	11

7.26 Has household routine been upset as result
of the patient's injury? (Q. 80)

Yes	No
2	9

7.27 Previous roles/relationships in family
undergone change? (Q. 81)

No change	Some changes	Major changes
3	5	3

(plus description - refer case studies section)

7.28 What effect has the injury had on the
relationship/marriage? (Q. 82)

N/A	No effect	Some effect	Major effect
2	1	6	2

(plus description - refer case studies section)

7.29 What effect has the injury had on the
sexual relationship? (Q. 83)

N/A	Some effect	Major effect
8	1	2

(plus description - refer discussion)

7.30 What effect has the injury had on the
family unit? (Q. 84)

No effect	Some effect	Major effect
1	7	3

(plus description - refer case studies section)

* Q. 85 - Any other issues? - descriptive (refer case studies section)