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PSYCHOSOCIAL OUTCOME AND FAMILY BURDEN AFTER TRAUMATIC BRAIN INJURY

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Abstract

The persistence of psychosocial symptoms after severe head injury has been identified as one of the main long-term difficulties facing such patients and their families. Not only have such problems proved persistent, they have been found to present particular problems for community re-entry including return to work. They have been associated in particular with stress on carers and also with disruption of family activities and health. Given that so many survivors of severe head injury rely on their families for long-term support, this topic has attracted increasing attention.

The present study described the psychosocial problems after severe head injury and their relationship to various "burdens" on carers and the wider family based on a group of 54 patients studied at 3, 6, and 12 months post-injury. Replication and extension of some findings is made through study of a multi-centre internationally collected group of 562 survivors of severe head injury.

The persistence of psychosocial problems is noted alongside their differing relationships to various aspects of "burden". Aspects of burden, and especially of social isolation, present challenges especially for those working in rehabilitation and community re-entry programmes.

LIST OF CONTENTS

(Appended reprints are attached after the Figures).

AUTHOR'S DECLARATION

Certain material based upon, or partly based upon, the data which form the subject of this thesis have been published previously. The thesis is based on joint research and the nature and extent of the author's individual contribution is described in chapter 6 ("Method") and in Chapter 8 ("Further study - European Brain Injury Society (EBIS) project").

Since this research was undertaken, three papers have been published directly based on the data collected. They are as follows:

> McKinlay W.W. and Brooks, D.N (1984). Methodological problems in assessing psychosocial recovery following severe head injury. Journal of Clinical Neuropsychology, 6, 87-99.
>
> McKinlay W.W. Brooks, D.N. Bond, M.R. Martinage, D.P. & Marshall M.M. (1981) The short term outcome of severe blunt head injury as reported by relatives of the injured persons. Journal of Neurology, Neurosurgery, and Psychiatry, 44, 527-533.
>
> McKinlay, W.W. Brooks, D.N. Bond, M.R. 1983. Post-concussional symptoms, financial compensation and outcome of severe blunt head injury. Journal of Neurology, Neurosurgery, and Psychiatry, 46; 1084-1091.

As required, reprints are appended for ease of reference. Other papers have been published which included some of these data, but which had been added to by later research.

A recent review article has provided a basis for parts of the discussion:

McKinlay, W.W., Watkiss, A.J. 1996. Long-term management, IN Brain Injury and After: Towards Improved Outcome edited by F.D. Rose & D.A. Johnson, Chichester: Wiley.

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CHAPTER 1

THE EPIDEMIOLOGY OF HEAD INJURY

a) Introduction

Head injury is common but does not strike at random. The nature of the head injured population is described in this chapter. It is important to try to establish what biases the head injured population contains before injury so that we are not too quick to attribute a characteristic, or a deviation from average, to the effects of injury.

b) The size of the problem

Head injury is a major health problem in westernised countries and accounts for 9 deaths per 100,000 population per annum in the U.K. While this is less than 1% of all deaths, head injury nevertheless causes 15% of all deaths in the 15-24 years old age range (Jennett and MacMillan, 1981). Moreover, Field (1976) reports that over 142,000 people were admitted to hospital following head injury in England and Wales in 1972, and Strang et al (1978) estimate that 4 to 5 times as many cases attend Casualty as are admitted.

While figures of this sort give an indication of the extent of the problem, head injuries range in severity from trivial blows which cause little anxiety to major impacts which cause sudden death. Indeed, Jennett and McMillan note that:

> "It is not possible to state simply how frequently head injuries occur. No universal definition of practical value can be proposed to cover the many injuries known only to general practitioners, traffic police or officials at sporting events and those that are never reported unless complications develop" (1981, pp.103-104).

In introducing his important study of the epidemiology of head injury in England and Wales, Field (1976) limits his use of the term "head injury" to insult "...which carries some risk of trauma to the brain". Nevertheless the range of severity and types of injury present real problems of definition. Jennett (1976) lists the ten rubrics from the International Classification of Diseases which were taken to cover head injury in the Field Report. However, Jennett and Teasdale (1981) note that while these rubrics "...taken as a group cover most head injuries..." they are not mutually exclusive, the mode of their use is influenced by "local custom", and they do not directly reflect severity of injury.

Severity has been assessed in the past in a variety of non-standard ways including duration of unconsciousness and length of hospitalisation. However, standard methods of assessing severity have been developed and for some time the most widely used methods have been the Glasgow Coma

Scale (GCS) (Teasdale and Jennett, 1974) and duration of post-traumatic amnesia (PTA) (see Russell, 1971), although there are others. PTA is the period after impact during which new information is not registered and stored so that there is a failure of "continuous memory of ongoing events" (Teasdale and Brooks, 1985, pp.185-186). In 1961 the Lancet observed that PTA was "the best yardstick we have" for measuring the severity of blunt head injury and the authors of the Glasgow Coma Scale continue to stress the value of PTA (Teasdale and Jennett, 1974).

The concept of PTA and possible difficulties in its assessment will be discussed in Chapter 3. At this point, it will suffice to note Russell's suggestion that the significance of PTA may be considered in the following way. Taking "concussion" to indicate neuronal trauma rather than in the colloquial sense of indicating slight injury, "slight" concussion may be equated with PTA of under 1 hour; "moderate" concussion with PTA of 1-24 hours; "severe" concussion with PTA of 1-7 days; and "very severe" concussion with PTA of over 7 days (Russell, 1971, p32). To these labels, Jennett (1976) adds "extremely" severe concussion as being indicated by PTA of over 1 month.

More recently, it has been suggested by van Zomeren and van den Burg (1985) that these labels create an unduly pessimistic picture of the prospects for recovery given modern methods of investigation and management. They conclude that a cut-off of 13 days of post-traumatic amnesia between "severe" and "very severe" injury would be a better reflection of the outcomes they reported. They suggest that this is probably because of improved medical and psychological care in the time since Russell's classification was made (based on clinical studies up to about 1960) and the time their own study was conducted (on patients admitted in 1978 and 1979).

Given the difficulties of defining head injury and the need for a relevant diagnosis to be qualified by an estimate of severity (ideally GCS and/or PTA), it was in the past difficult to make a precise estimate of the number of people who sustain non-fatal severe head injury. However, there are now several estimates in the literature. Miller & Jones (1985) reported on all admissions in a single year to the Neurotrauma Unit in Edinburgh which serves a population of 1.2 millions. They reported that there were 1616 minor, 210 moderate, and 93 severe head injuries in one year, all as classified by Glasgow Coma Scale. Of these 42 severely injured died, together with 8 cases initially moderate and 7 initially mild, who deteriorated and died. There were 116 in all who, one month post injury, remained severely disabled or vegetative in terms of the Glasgow Outcome Scale. It seems likely that all these at least will have some rehabilitation needs and many will have significant limitations.

Other studies have provided estimates which might be said to be in the same "ball-park" in terms of the numbers of survivors with disabilities or with rehabilitation needs (e.g. British Psychological Society's (1989) report). It may reasonably be said that head injury is a common cause of disability, especially in the first half of life (Field, 1976; Jennett, Teasdale, Galbraith, et al. 1977; Marshall, Becker, Bowers, et al. 1983; Rimel and Jane, 1983) and although the number killed and seriously injured seems to be declining (Field, 1976), the number of disabled survivors remains substantial.

Whether the decline in mortality achieved by modern acute medical care has reduced morbidity to the same extent is less certain and is doubted by Newcombe (1982). Furthermore, given the lack of clear evidence that life expectancy is reduced, the number of years of disabled life ahead of these young injured people is very considerable.

The survivors of severe head injury, then, are a sizeable group whose importance as a clinical problem is given added point by the disproportionate numbers of young people injured with the risk at its highest for those in their late teens and twenties (Field, 1976; Jennett, Teasdale, Galbraith, et al. 1977; Marshall, Becker, Bowers, et al. 1983; Rimel and Jane, 1983).

c) <u>The characteristics of the head injured population</u>

The head injured also differ from the general population in a number of other ways. Field (1976) concludes a survey of British studies by noting that they "consistently showed an excess of males to females in hospital admissions for head injury" and that this was of the order of 4 to 1 for adults. Marshall et al (1983) reported on the U.S. National Traumatic Coma Bank which is intended to "become a major resource for the neurosurgical community" (p.282). They too report a preponderance of males, this time of 3 to 1. However, they point out that within each sex the age distribution is very similar with the major risk in late teens and twenties.

Over-representation of the lower social classes was noted by Field (1976) but he did not reach a firm conclusion on the notion that the head injured are - in general - a particularly "accident prone" group.

How these patients receive their injuries is also difficult to classify in a comprehensive yet exclusive way (Field, 1976; Jennett, and Teasdale, 1981). The distribution of causes varies with severity of injury and local cultural factors. Jennett and Teasdale (1981) note that of patients seen in Accident & Emergency then sent home - presumably indicating mild injury - only 13% had been in road traffic accidents (RTAs). However, in a survey of severe head injuries in three countries, 58% of 694 patients had received their injuries in RTAs, the figures varying according to centre: 53% of the Glasgow patients were injured in RTAs, 78% in the Netherlands and 47% in Los Angeles (Jennett, Teasdale, Galbraith, et al. 1977).

The same paper provides a further illustration of the effect of local cultural factors. In Glasgow, where the present study was carried out, assaults (19%) and drunken falls (17%) were also significant causes of injury as they were in Los Angeles, but in the Netherlands assaults and drunken falls each accounted for only 1% of injuries.

To this list of causes of severe head injury may be added domestic accidents (between 8% and 23% in the studies cited by Field (1976)); and accidents at work (between 2% and 9% in the study of severe head injury in three countries (Jennett, Teasdale, Galbraith, et al. 1977)). Sport, including falls from bicycles and horses, is also recorded with some regularity as a cause of injury. The influence of alcohol, too, has been reported (Strang, et al. 1978; Jennett, Murray, MacMillan, et al. 1977) and in the former study, evidence of recent alcohol consumption was more common in men who had fallen or been assaulted than in those injured in other ways.

Marshall et al (1983), reporting on the U.S. Traumatic Coma Data Bank, broke down cause of injury by age. They found that motor vehicle accidents accounted for the majority of injuries in those aged 0-4, 15-29, and 30-59. In 19-29 year olds, where risk of injury is highest, motor vehicle accidents accounted for 82% of cases while falls accounted for only 4%. However, in those over 60 years old motor vehicle accidents and falls accounted for 36% and 47% respectively.

Taking this information together, the picture which emerges is that males heavily outnumber females and that the young and relatively unskilled are over-represented. Motor vehicle accidents account for half or more of the injuries but local variations, particularly in cause of injury, are evident.

A recent Canadian study provides some further support for this general picture (Wong, 1993). 498 consecutive admissions to a traumatic brain injury rehabilitation programme in Toronto were studied. The male to female ratio was 3.5:1 and the unskilled and unemployed were over-represented, but only amongst males.

d) **Reaching the neuroservice**

The process by which patients reach the neuroservice (and the research studies) introduces a further source of variation between patient samples. The examples given by Jennett et al (1977) illustrate this well. Only 4% of head injuries admitted to hospital in the West of Scotland catchment area were transferred to the Institute of

Neurological Sciences in Glasgow. Those transferred were severely injured or were judged to be deteriorating. On the other hand, at the Dutch centres included in the same study, almost 90% of head injuries were admitted to the neuroservice within about 2 hours of injury. In Los Angeles, most head injured patients reached the neuroservices within 6 hours of injury, although industrial injuries were under-represented for reasons related to private insurance guarantees.

In view of the variability between centres and the clinical judgements involved in triage, it is likely that the head injured population reaching neuroservices varies both from centre to centre and also from time to time. This may also occur in a more explicit way when admission procedures are changed as a matter of policy (e.g. see Jennett and Teasdale, 1981). This needs to be borne in mind in reporting and interpreting studies: researchers should describe their samples carefully in terms of demographic and clinical features in order to allow comparisons to be made with others' findings.

CHAPTER 2

THE NEUROPATHOLOGY OF HEAD INJURY

a) Introduction

As well as the characteristics of the people most likely to be injured, the kind of injury generally suffered by the brain as a result of head injury is another important issue which sets the context for this thesis. Therefore, a brief account will be given of neuropathological studies which help elucidate the nature of the injury to the brain.

A collision between the head and a hard surface, whichever is in motion, may result in injury to the brain (although the brain can also be injured in other ways). As Ripperger (1975) notes, this much can hardly be disputed, although the pattern of forces applied to the brain and the resultant damage have presented a complex problem for researchers in this area. In reviewing experimental studies of the mechanical processes which may be involved, Ripperger considers a variety of variables and issues. Acceleration may be translational (linear) or rotational, the former possibly causing cavitation effects resulting in contre coup injury and the latter causing rotational movement of the brain with attendant fibre shearing and contusions where the brain is confined by bony structures. Other variables include structural characteristics of skull and brain. Thus, skull thickness and rigidity together with direction of blow may be expected to have an effect; and the pattern of shear strains may be complicated where sharp changes in stiffness properties occur between white and grey matter.

In the clinical situation, however, Jennett and Teasdale (1981) note that it will seldom be possible to ascertain with any degree of precision the magnitude and direction of blows which in any event may be multiple. Moreover, secondary damage rather than the direct effects of the blow itself may be important. Such secondary damage includes intracranial haematoma, brain swelling, hypoxic and ischaemic damage, and late infection (Jennett and Teasdale, 1981; Adams, 1975). Our knowledge of the nature and extent of the damage to the brain caused by severe head injury has been increased considerably by the neuropathological studies of Adams and his collaborators. Primary and secondary damage are each outlined then there is a brief discussion of recent research which now blurs these distinctions.

b) <u>Primary damage to the brain</u>

Three major kinds of damage which may occur immediately on impact are described by Adams (1975). Firstly, the skull may be fractured. Miller notes:

> "The principal significance of damage to the structures that surround the brain is first that it may be associated with bleeding that, if inside the

> cranial cavity, soon becomes an urgent problem because of the limited space available for the expansion of the haematoma, and secondly that the introduction of infection to the intracranial cavity is facilitated. In this respect, the integrity of the dural envelope is of considerable importance. Once this is breached, infection is a strong possibility. If the dura remains intact, intracranial infection is rare" (Miller, 1983, p.40).

Depressed open fractures are associated with a higher incidence of post-traumatic epilepsy, infection, and focal damage, while basal skull fractures are associated with a much increased risk of infection. However, many patients with severe diffuse damage have no skull fracture: the fracturing of the skull may serve to absorb some of the impact (Adams, 1975).

Secondly, contusions of the grey matter are "the classical features of a blunt head injury" (Adams, 1975, p.38): irrespective of impact site, the brain areas occupying the anterior and middle cranial fossae are the most commonly contused. Thus, the frontal poles, orbital gyri, cortex above and below the Sylvian fissures, the inferior and lateral temporal lobes, and the infero-lateral angles of the occipital lobes are all particularly vulnerable. The damage in these areas is related to the resistance offered by the sphenoidal ridges and other irregular bone surfaces on the base of the skull and consequently the crests of the gyri are most likely to be contused. However, extensive contusion may produce no loss of consciousness: it is the resulting oedema, haemorrhage, and swelling, and their consequences that are important in that respect (Jennett and Teasdale, 1981).

Thirdly, there is evidence of shearing damage to nerve fibres on impact (white matter lesions). This view was first proposed by Stritch in 1956, although there was at first some controversy over whether shearing is directly due to impact or is due to vascular and anoxic damage. A study by Adams et al (1977) appears to resolve this in favour of the impact theory: cases were found with no evidence of vascular or anoxic or other secondary complications who had demonstrable lesions which were explicable in terms of impact.

A number of experimental and neuropathological studies have helped to clarify the nature of diffuse shearing damage to nerve fibres. Reviewing experiments with animals, Adams et al (1982) noted that animals with their heads fixed were more difficult to concuss than those whose heads were free to undergo rotational acceleration. Moreover, in early experiments it proved difficult to produce prolonged traumatic unconsciousness in animals: rather they were concussed briefly or else they died. However, when the duration of the pulse of impact was increased, the duration of unconsciousness was also increased.

A series of experiments conducted in association with Gennarelli (Gennarelli et al, 1982b) produced traumatic coma in 45 monkeys by non-impact acceleration. Such acceleration or inertial loading does not involve contact between the head and another object and led Adams et al (1982) to distinguish contact aspects of trauma (e.g. skull fracture, scalp laceration, extradural haematoma) from inertial effects. The latter are held to include diffuse axonal injury with the magnitude and duration of the inertial pulse crucial and lateral motion more damaging than forward/backward or oblique motion.

Adams et al (1982) enumerate three features of diffuse axonal injury which are in evidence post mortem. Firstly, there is a lesion in the corpus callosum which is haemorrhagic in those who survive for only a few days and is represented by a scar in longer term survivors. Secondly, there is a lesion in the dorso-lateral quadrant of the rostral brain stem in the region of the superior cerebellar peduncle. Thirdly, damage to axons may be recognised microscopically in a variety of ways, the form that this takes depending on the duration of survival post trauma. In those who survive only briefly, retraction balls are evidence that the axons have sheared, whereas in those who survive many months the bulk of the white matter is reduced with corresponding ventricular enlargement.

A further study (1982) by Adams is a comparison of 45 cases of diffuse axonal injury (DAI) with 132 cases of fatal head injury without DAI. DAI cases differed from non-DAI cases in a number of respects. No DAI case had a lucid interval whereas 44% of non-DAI cases had a total or partial lucid interval. 73% of DAI cases sustained their head injuries in road traffic accidents against 42% of non-DAI cases. DAI cases were less likely to have skull fracture, intracranial haematoma, brain swelling or raised intra-cranial pressure than non-DAI cases and they also had less contusion. The authors conclude that DAI cases form a distinct clinical and pathological group.

The lack of a lucid interval suggests that DAI occurs on impact and taking together the 29% incidence of skull fracture in the DAI group as against 86% in the non-DAI group and also the fact that DAI was more likely to result from road traffic accidents these authors suggest:

> "It is therefore possible that during road traffic accidents ...... rotational acceleration can occur in the absence of direct focal trauma to the skull, as for example in an impact to the face resulting in head acceleration but no direct skull impact" (Adams, 1982, p.562).

It is important to note that the shearing of nerve fibres at impact is not confined, as has sometimes been suggested, to the brain stem. Where primary damage to the brain stem occurs, it does not do so in isolation (Jennett and

Teasdale, 1981; Adams et al. 1980; Adams et al. 1982) but is part of more widespread damage as was predicted by Ommaya and Gennarelli (1974). They suggested, on the basis of experimental studies with primates, that rotational shearing injuries would affect the brain in centripetal sequence: the cortical areas would be affected first with more severe injuries also affecting the diencephalon and then the mesencephalon.

Indeed Jennett and Teasdale (1981) note that attention has shifted away from the brain stem as the site of the lesion responsible for concussion. In support of this shift, they also note that head injuries seldom demonstrate rapid development of the vegetative state or the locked-in syndrome without several days coma first, unlike patients with primary vascular brain stem lesions. They suggest, too, that fibre shearing lesions of a degree that tear some axons and stretch others, the latter leading only to temporary failure, is a possible explanation for both concussion and the cumulative effect of repeated mild injuries.

c) <u>Secondary damage to the brain</u>

The secondary effects of injury include the delayed effects of impact and other non-direct effects which may arise from other injuries or as complications. Of the former, intracranial haemorrhages are especially important and they are also reviewed by Adams (1975, 1982). Most commonly these result in the formation of extradural, subdural, or intracerebral haematomas. Extradurals are the least frequent of the three and result from tearing of a meningeal artery, nearly always associated with skull fracture; subdurals are attributed to ruptured blood vessels in the subdural space and to contusions; and intracerebral haematomas are usually subfrontal or temporal or occur in deep cerebrum due to shearing damage to small blood vessels. Where subdurals and intracerebral haematomas occur in continuity there is said to be a "burst" lobe.

While intracranial haematoma develops in a minority of the head injured cases admitted to hospital, it is nevertheless of importance. Intracranial haematoma was found in 75% of a series of "talk and die" patients (1975); delay in treating intracranial haematoma was the most common "avoidable" factor in a study of "talk and die" patients (Rose et al. 1977); and a further study (Marshall et al. 1983) identified subdural haematoma as significantly more common in patients who talked and died than in those who survived after talking and deteriorating. Jennett and Teasdale (1981) note that many disabled survivors have haematomas evacuated in time to save their lives but too late to restore brain function fully. Although haematomas are classed as secondary or delayed effects of impact, in a series of fatal injuries reported by Adams et al (1980), only 50% of cases with extradural haematomas and 57% of those with subdurals had had a lucid interval.

Other damage may occur which is a delayed consequence rather than an immediate result of impact. Contusions, with their associated swelling, and intracranial haematomas are significant partly because they act as intracranial expanding lesions producing midline shift, convolutional flattening, tentorial herniation, and sometimes fatal brain stem damage (1975). With the rapidly expanding lesions which occur after head injury, raised intracranial pressure (ICP) is likely to accompany these processes and the combination of raised ICP and shift produces vascular damage (Jennett and Teasdale, 1981).

Brain swelling can also be important in contributing to raised intracranial pressure: its cause in head injury is not well understood but it is commonest in localised form adjacent to contusion and may also occur over the whole of one or both hemispheres (Adams, 1982).

Other sources of secondary damage noted by Adams are ischaemic brain damage (diffuse or focal), damage to hypothalamus and pituitary gland (although it is possible that such damage is primary rather than secondary), and infection (especially meningitis). These various forms of secondary damage, which are not directly and immediately occasioned by impact, are those which neurosurgeons seek to limit or prevent in treating the head injured, while at the same time ensuring favourable circumstances for recovery from primary brain damage (Teasdale, 1976).

d) Cascades and secondary insults

Before summing up the pathological findings which have a bearing on the present research, it is necessary to comment on more recent developments. It has become clear that "primary" damage is in fact more of a process than an event, and also that secondary insults are extremely common.

From research in recent years, the differentiation between primary and secondary insults has become less distinct. At one time the main theory as regards axonal injury, thought to be the damage most characteristic of trauma, was that it occurred at the time of impact in injury. However, it is now thought that it may continue to develop over a number of hours (Povlishock, 1992). The precise mechanisms and timing that underlie this process are not yet fully understood. However, severe insult to the brain starts a complex biochemical "cascade" that leads to cell death arising from pathological changes in the brain's neurochemical systems. Some recent approaches to management of brain injury involve attempting to interrupt these cascades through pharmacologic treatment to stimulate repair of damaged neurons or by blocking some of the degenerative processes caused by the cascade. (McIntosh, 1994).

It has also recently been shown that secondary damage in fact occurs more frequently than previously thought. In a study where there was continuous computer-administered monitoring of patients, secondary insults were found in 91% of cases and at least one episode of raised intracranial pressure (ICP) in 84%. 32% of the insults detected in this way were not detected by a skilled nursing team making observations on a half-hourly schedule, and the mean duration of "missed" insults was 14 minutes (Jones et al. 1994).

Teasdale (1995) has noted that primary and secondary damage "are becoming less easy to separate". Nevertheless there are clinical patterns. Where there is loss of consciousness or signs of neurological damage at time of injury, followed by improvement in clinical state, mainly primary damage has been suffered. Where there is no loss of consciousness at the moment of injury but then deterioration, mainly secondary damage is present. There may also be mixed pictures.

e) Conclusions

There are two caveats. Firstly, cases who reach the pathology department of a neurosurgical unit inevitably represent a biased sample of severe head injuries. And secondly, it is not possible to be precise about the extent of damage in an individual survivor.

While neuro-imaging will reveal haematoma, midline shift of major proportion, etc, much of the damage following impact, especially diffuse axonal injury, is only evident on microscopic analysis of carefully prepared brain specimens at post-mortem (Adams, 1975).

Nevertheless, an often quoted study by Oppenheimer (1968), which was primarily concerned with methods of detecting minute brain lesions, has provided evidence that diffuse axonal damage is not confined to injuries so severe that they are fatal. In five of the cases reported in this study in which there was evidence of diffuse axonal injury:

> "..... the cerebral injury was clinically trivial consisting of "concussion" lasting only a few minutes." (Oppenheimer, 1968, p.301).

These patients had died from other causes "...usually fat embolisms or pneumonia" (ibid).

Jennett and Teasdale (1981) suggest that the "final common path" for lesions which cause unconsciousness is probably the inactivation of sufficient cortex whether by primary damage (shearing and contusion) or secondary damage (including raised intracranial pressure, haematomas, and hypoxic and ischaemic damage). While the same authors note that impact and secondary damage may be difficult to distinguish and that the mechanisms of damage are incompletely understood, it may be that different explanations are required for immediate deep persisting coma on the one hand and secondary coma following a lucid interval on the other.

In particular, the former may be due to severe impact damage to the white matter leading to the disconnection of areas of cortex. It is particularly likely that diffuse axonal injury is the main pathology when the picture is not complicated by evidence of significant secondary pathology. On the other hand, where there is a lucid interval, secondary damage will be the key pathology. This will comprise a number of possible elements, perhaps in combination, including contusions, oedema and haematoma; raised intracranial pressure and herniation; and impaired perfusion and ascending reticular system dysfunction. In most head injuries both types of pathology will be present to some degree.

From the point of view of the present thesis, the major conclusion to be drawn is that damage to the brain is likely to be widespread, patchy and unevenly distributed; but compared with, for example, missile wounds where there is complete destruction of an area of the brain, in non-missile injury the picture is of reduced efficiency of function over a wide area of the brain. Nevertheless, more than one mechanism seems to underlie this reduced efficiency, and a more articulated approach to assessing the nature and severity of injury may be productive in future. This theme will be taken up again in the course of the next chapter when the assessment of severity of injury is considered.

CHAPTER 3

ASSESSING THE PROSPECTS FOR RECOVERY

a) Introduction

This chapter will provide an account of the indices which are used in clinical practice to document the severity and the nature of injury. Glasgow Coma Scale scores and duration of post-traumatic amnesia are probably the most widely used measures of severity of closed head injury, although more recent research suggests that evidence of focal damage should not be ignored in predicting outcome.

b) Severity of Injury

In view of the complex pathology of head injury, it is perhaps remarkable that the immediate consequences should be uniform in so many cases. Russell's (1971) description has often been quoted:

> "The immediate effects of concussion are usually that the individual drops to the ground motionless, often with an arrest of respiration, and at this stage basic reflexes such as corneal responses may be abolished. After respiration returns, restless movements appear and by very gradual stages the patient begins to speak, resist interference, makes a noise, and becomes restless, talkative, abusive and irritable in one way or another. Slowly his speech becomes more intelligible and then as the effect of the trauma

> wears off he looks around wondering where he is: the period of traumatic confusion is at an end, but he has no recollection of any event that occurred since the injury. Further there is a short period before the injury that he does not remember - the so-called period of retrograde amnesia" (Russell, 1971, p.1).

This sequence of events has suggested two main methods of measuring severity of injury. In 1928 Symonds proposed duration of unconsciousness as a measure of the extent of cerebral damage. Degree of duration of coma has proved a reliable guide to the severity of diffuse (but not focal) brain damage and is also crucial in monitoring the early progress of the patient (Jennett and Teasdale, 1981).

c) <u>Glasgow Coma Scale</u>

The lack of soundly based reliable measures led Teasdale and Jennett (1974) to publish what has become known as the Glasgow Coma Scale (GCS) in which three aspects of the patient's responsiveness are evaluated: the stimulus required to induce eye opening, the best verbal response, and the best motor response. These authors have defined "coma" as "not obeying commands, not uttering words, and not opening the eyes" (Jennett and Teasdale, 1981, p.80).

Responsiveness on each of the three aspects of the scale can be summed (Jennett and Teasdale, 1981, pp.77-81) to give a total score ranging from 3 (least responsive) to 15.

The authors report that:

> "...all combinations that sum to 7 or less define coma, as do 53 per cent of those totalling 8; thus 90 per cent of all observations summing to 8 or less, and none of those that add up to 9 or more, define coma" (p.81).

It has become customary to label GCS (after resuscitation) of 3 to 5 as denoting "very severe" injury; GCS 6 to 8 as "severe" injury; GCS 9 to 12 as "moderate" injury; and GCS 13 to 15 as "minor" injury.

d) Post-traumatic amnesia

In 1932 Russell proposed that the time taken to recover full consciousness, i.e. the duration of post traumatic amnesia (PTA), would provide a measure of severity. This period begins at impact and is taken to end "at the time from which the patient can give a clear and consecutive account of what was happening around him" (Russell, 1971, p.13). PTA can be determined by careful retrospective questioning, with two caveats. Firstly "islands" of memory may be followed by further amnesia for a day or two: it is the beginning of continuous memory which is taken by Russell to denote the end of PTA. Secondly, even although a patient appears to be aware of current events, these may not be recalled later: duration of PTA should be checked by retrospective assessment (Russell, 1971).

It has been suggested that PTA is "the best yardstick we have" for measuring the severity of blunt head injury" (Editorial, Lancet, 1961) and it has certain practical advantages:

> "It is often important to be able to assess the severity of injury long after the event, perhaps months or years later. The original notes are then seldom available and even when they are, they seldom contain as much information as is hoped. In such circumstances the PTA enables the severity of diffuse brain damage to be assessed......" (Jennett and Teasdale, 1981, p.90).

As well as retrospective inquiry, the question of whether the ending of PTA and the return of full orientation in person, place and time represent one and the same event has attracted attention. A clear, operationally specified testing procedure for defining the end of PTA could provide "a sharper and more consistent diagnostic and predictive tool" (Artiola I Fortuny et al. 1980, p.377).

Artiola I Fortuny et al (1980) compared neurosurgeons' estimates of PTA duration in 80 patients with the estimates of neuropsychologists. The former were presumably based on retrospective questioning. The latter were based on daily testing intended to determine when full orientation returned: in particular, PTA was judged to have ended on the first of three successive days on which there was correct recall of simple to-be-remembered items.

While the estimates of neurosurgeons and neuropsychologists were reported to match well, it should be noted that the average PTA duration was short. About half of the 80 cases had PTA of less than 10 minutes and only 4 or 5 (depending on which ratings are consulted) had over 1 day of PTA. This study cannot therefore be taken to provide evidence that in the more severely injured the return of orientation and the ending of PTA are the same event.

Teasdale and Brooks (1985) have provided a review of the topic of traumatic amnesia. They note, in relation to PTA, that various authors have tried to overcome the problem of assessing PTA duration reliably and conclude that PTA can indeed be measured reliably provided the caveat about "islands of memory" is heeded. As regards the association between the ending of PTA and the regaining of orientation, these authors conclude their review with the observation that:

> "It may be that the association between PTA and disorientation is more a reflection of their being different processes both disturbed to a similar degree by injuries of similar severities" (Teasdale and Brooks, 1985, p.188).

The duration of PTA is usually constant with the shrinkage which affects retrograde amnesia (RA) seldom observed (e.g.

Teasdale and Brooks, 1985). PTA usually has its onset at impact but occasionally the injury is recalled and there follows a period of "delayed PTA": presumably this indicates that secondary complications rather than impact damage are significant. Nevertheless, only where the initial concussion is very slight is there likely to be a well developed lucid interval before secondary complications have their effect (Russell, 1971).

e) Severity and underlying mechanisms of injury

As indicated in the discussion of neuropathology, phenomena such as haematoma, which are in a sense focal, are of significance mainly because of the diffuse effects they produce by means of herniation and shift. Moreover, brain swelling, which is a secondary effect of injury also results in diffuse damage. In such cases the onset of coma and post traumatic amnesia may be delayed. For example, in Jennett et al's study of severe head injury in three countries (1977) all 700 cases had at least 6 hours' coma and 91% had over a week of PTA; however, around 30% had a lucid interval and around 12% were recorded as having been "completely lucid", ie considered "sensible and normally alert" (Jennett et al, 1977, p.293).

Where the onset of impaired conscious level was delayed the underlying neurophysiological mechanism will presumably not be diffuse axonal injury. However, in cases where the patient suffers immediate deep and persisting coma, it will be possible that diffuse axonal injury has occurred. But it is possible that secondary damage resulting from brain swelling or space occupying lesions, prolong coma and PTA beyond the duration which would have resulted from uncomplicated DAI. In short, despite the apparent simplicity of coma and PTA as measures, the underlying processes cannot be presumed to be homogenous.

Nevertheless, coma and PTA have been widely adopted as measures of the severity of diffuse injury and there is considerable evidence for their utility. For example, Jennett and Teasdale (1981) report that in a large series of patients, 83% of those with PTA of less than 14 days, made a good recovery as measured by the Glasgow Outcome Scale (1975). On the other hand only 27% of those with a PTA of more than 28 days made a good recovery. The importance of coma as a predictor of eventual outcome has also been well documented (see Jennett and Teasdale, 1981) and depth of coma as assessed by the Glasgow Coma Scale is important in monitoring the patient in the early stages as well as in making predictions about outcome.

f) **Nature of Injury**

A number of authors have suggested that measures of diffuse head injury may only tell part of the story about the future outcome for patients with non missile head injury. Gennarelli et al (1982a) note that coma of more than 6 hours has been associated with less than optimal outcome, but raise the question of whether the cause of the coma is important. They studied 1,107 cases who were divided into 7 different groups with respect to kind of injuries sustained.

In all, seven main lesion groups were formed. As regards the focal lesions, patients were so described if CT scan demonstrated a space occupying lesion causing a mass effect thought to be responsible for the coma. There were 4 focal lesion groups, namely operated extradural (epidural) haematoma; acute subdural haematoma (operated); other focal lesions - operated; and other focal lesions - not operated. A further three lesion groups were diffuse brain lesions: coma 6-24 hours; coma more than 24 hours but not decerebrate; and coma more than 24 hours with frequent episodes of being decerebrate or flaccid. (Those who were in coma for less than 6 hours were of course not judged to have had injuries of sufficient severity to warrant inclusion in the study).

The groups obtained in this fashion were divided into those with an initial GCS score of 3 - 5 ("more serious") and 6 - 8 ("less serious"), producing 14 groups in all. These 14 lesion categories were then cross tabulated with the 5 outcome categories in the Glasgow Outcome Scale, yielding a total of 70 cells.

Gennarelli et al (1982a) point out that for patients with injuries of equivalent severity (as assessed by the Glasgow Coma Scale) differences in the cause of lesion may be of major importance: cause of lesion accounted for differences of up to two times in mortality and up to nine times difference in the percent of patients making a good recovery.

Worst outcome was associated with subdural haematoma which accounted for 45% of all deaths in this series and the worst outcome in survivors with only 22% of these patients attaining good recovery or moderate disability (Glasgow Outcome Scale). Diffuse head injury where there was coma of more than 24 hours was also associated with poor outcome: this group accounted for 32% of all deaths although 45% of them attained good recovery or moderate disability.

The best outcome was associated with patients with epidural haematoma in whom 63% made a good recovery or had moderate disability and those with diffuse head injury with a coma of less than 24 hours in whom 78% achieved a good recovery or moderate disability.

Lobato et al (1986) studied 309 severe cases drawn from a total of 2,601 head injury admissions. They identified eight patterns of injury on the basis of CT scan evidence. It is unfortunate that for some of their analyses they group together cases with epidural and subdural haematomas which in the Gennarelli et al study (1982a) were associated with particularly good and particularly poor outcome respectively. Nevertheless, Lobato et al (1986) did also conclude that subdural haematoma was a poor prognostic sign. This study, too, provides evidence that the nature of injury is of importance. Others (Johnson and Almi, 1978) have suggested that the extent of mid-line shift, indicating swelling or a space occupying lesion, may add to prediction of outcome combined with 24 hour post injury Glasgow Coma Scale scores.

In short, while depth and duration of coma and duration of PTA are of considerable importance, the latter having been described as "the best yardstick we have" (Lancet editorial, 1961), nevertheless recent evidence suggests that other features of injury could profitably be taken into account in order to improve predictions about eventual outcome. Such considerations have led Stein and Spettell (1995) to propose a Head Injury Severity Scale (HISS) which has a severity dimension based on the Glasgow Coma Scale and a second dimension of complications. This scale was published in 1995 and its acceptability to clinicians and its utility remain to be established.

g) <u>The Process of Recovery</u>

The route by which patients travel from the states of coma and PTA to their eventual final level of recovery is not well understood. Many possible mechanisms of recovery have been proposed and Johnson and Almi (1978) list a number of these.

Diaschisis theory (originally proposed by Von Monakow) postulates a temporary traumatic interruption of neural organisation or integration. Substitution and equipotentiality theories imply that in the healthy organism there is a degree of neural redundancy so that a secondary system or other brain area can take over the function of damaged systems. Regeneration and collateral sprouting theories propose that new growth occurs in damaged neurons or adjacent tissue. Denervation super-sensitivity proposes an increased sensitivity to transmitter substance i.e. perhaps high post synaptic receptor populations may underlie the recovery of damaged areas. A further theory is less a theory of recovery than of adaptation and it is that the patient changes his behavioural strategy so as to accommodate to neural deficits which have been incurred.

The same authors acknowledge that age is an important factor and that the young tend to do better, although recent studies of head injured children are not so encouraging (see Johnson and Rose, 1996). It seems that the infant brain may well be more vulnerable to insult, with vulnerability again greater in later life.

Moreover, delayed deficits are sometimes observed in young animals: this may arise when a neural area, which is not yet committed to a behaviour, is destroyed. No behavioural deficit would be observed initially, but later, when this area would (maturationally) have been committed to a particular function a behavioural deficit will emerge.

Johnson and Almi (1978) suggest that the particular areas of brain injury may also be of importance, and in regard to adult animals, discuss the ideas of a loose and tight coupling. They suggest that recovery is greatest for areas such as association cortex, which are said to be loosely coupled, and recovery least for tightly coupled areas such as primary motor cortex or sub cortical regions. The tightly coupled areas are more closely dedicated to particular functions than the loosely coupled areas.

A further concept which arises in this area is suggested by Braun (1978), again on the basis of animal work. It is that stimulation as well as time are required for recovery: on the basis of animal experiments, he suggests that recovery may not occur in organisms starved of stimulation.

A discussion of the process of recovery from head injury was offered by Bond and Brooks (1976). These authors, on the basis of four studies concerning 719 individuals with closed head injury, noted that the greater part of mental and physical recovery occurs in the first 6 months after injury. They noted that there might be "critical periods" for treatment and stimulation to have maximal effect, but that these remained to be detected, and that later recovery appeared to be an adaptation to fixed mental and physical deficits.

Despite the development of these concepts, the precise nature of recovery from head injury remains obscure. Thus Jennett and Teasdale (1981) write:

> "recovery of functions after acute brain damage is a remarkable phenomenon the mechanism of which is almost wholly obscure" (p.253).

Jennett (1983) suggests that recovery probably occurs in stages. Where recovery occurs in the first minute after injury, it is likely the dysfunction will have been transitory and may not have any structural component; where recovery takes several days, he suggests that it may be due to temporary structural abnormalities such as oedema or vascular permeability; and where recovery takes months or years, it is harder to explain. The last mentioned may be due to restoration of activity in the structures which were injured or in the diversion or neural activity to others.

h) <u>Conclusions</u>

The severity of injury is a key variable, and is usually assessed by Glasgow Coma Scale scores and duration of post-traumatic amnesia. However, severity is not the whole story and certain features - such as subdural haematoma - have an influence on outcome independently of severity.

Recovery is a slow process, which may reflect a number of underlying processes.

CHAPTER 4

GLOBAL, PHYSICAL, AND COGNITIVE OUTCOME

This chapter is concerned with global outcome studies, and also with studies of physical and cognitive outcome. These are reviewed briefly to set the context for the next chapter, which introduces the main topic of the thesis, psychosocial outcome.

a) Global Outcome Studies

In any consideration of detailed aspects of brain injury outcome, it is important to remember the seriousness of a brain injury, and that overall mortality and morbidity remain high.

Miller (1992) reported that mortality after severe injury is about 35%. Others have reported higher figures and it is fair to say that with advances in overall management the mortality rates have declined. Nordstrom et al (1989) reported a mortality rate in Lund, Sweden of 48% in 425 patients admitted between 1977 and 1982. From 1983 there was a change in the management of brain injury towards a "more aggressive" policy which included better triage and increased intra-cranial pressure monitoring. In 162 patients admitted in 1983-1984 mortality was 35%. These same authors also reported that the morbidity in survivors decreased: in the earlier period, 39% of the sample reached

Good Recovery or Moderate Disability (Glasgow Outcome Scale) 6 months after injury; while in the later period, 54% reached Good Recovery of Moderate Disability by 6 months post-injury.

Jennett and Teasdale (1981) reported on a sizeable data base (over 500 survivors at 3 and 6 months post-injury, and nearly 400 at 12 months). By 12 months, 50% had made a Good Recovery in Glasgow Outcome Scale terms, with the other half in the Moderate Disability (31%), Severe Disability (16%), and Vegetative State (3%) groups. Of those in the Good Recovery or Moderate Disability categories at 12 months, 69% had achieved this by 3 months after injury and 90% by 6 months. However, these are broad categories, with only three categories (Good Recovery, Moderate Disability, and Severe Disability) to encompass the full range of sentient survivors, so that clinically worthwhile changes may occur without a change in Glasgow Outcome Scale grouping.

Major predictors of outcome after head injury were identified as Glasgow Coma Scale (GCS) score, pupillary size and reaction, and age by Bullock & Teasdale (1990). GCS is, of course, one of the two main measures in use of injury severity. The other of these measures, duration of Post Traumatic Amnesia (PTA) should not be overlooked. Thus, Jennett and Teasdale (1981), reporting on 486 survivors, found that 83% of those with less than 14 days of PTA made a Good Recovery (Glasgow Outcome Scale) at 6 months; for those with PTA of 15-28 days the figure was 66%; and for the most severe, with PTA over 28 days, the figure was 27%.

One reason for using PTA duration is that it may be estimated by careful interviewing in virtually all cases. GCS scores on the other hand were not always available when this study was carried out, especially on patients admitted to outlying hospitals and not transferred until later to the neuroservice.

Another reason for considering PTA duration is that there is a subset of patients whose GCS score is never particularly depressed but who have long PTAs. Wilson at al (1988) have identified this group as patients with frontal and temporal contusion as the characteristic neuropathology: in these cases it is the long PTA (implying more severe injury) rather than their modestly depressed GCS score (implying less severe injury) which are predictive of outcome.

Another way of forming an impression of the general effects of brain injury is to consider rates of return to work. Detailed discussion of this would form a topic on its own and the data of the present study have helped provide a contribution to the literature in this area (Brooks et al. 1987). In that study, which reported on an extended follow-up of 2 to 7 years, only 29% returned to work overall. While there were some individuals who left or resumed work over that period, there was no overall improvement in the percentage in work from 2 to 7 years post-injury. The above study was based on a group of patients with a median PTA of between 15 and 28 days, looking to be biased towards the higher end of the range. It is important in this area to qualify any reports of return to work with an indication of injury severity.

Another broad approach which helps convey overall outcome is recent work on service planning. Tennant et al (1995) reports on 190 patients, followed up at 7 years post-injury. Their cases were selected from two units, one mainly serving an urban area and the other mainly serving a rural area. Patients were included who were in various categories: "brain injury, unclassified", "compound skull fractures", "extradural haematoma", "acute subdural haematoma", and "intracerebral haemorrhage" (not non-traumatic). The sample had a mean PTA of 19.4 days, similar to the median for the present sample of 21 days. Follow-up was at a mean of 7.1 years with a range of 1.9 years to 13.3 years. At follow-up, 23% were Moderately Disabled or worse on the GOS, including 7.4% who died subsequent to discharge. Of the survivors, 17% failed to make a Good Recovery (in GOS terms). However, 36% were failing to occupy their time in a meaningful way. Patients reported problems with memory (56%), irritability (49%), and temper (45%) and relatives agreed to a reasonable extent, the least agreement being on emotional changes, an observation previously made by the present author (McKinlay and Brooks, 1984).

It is clear then that the long-term outcome after brain injury may well include significant disability, and problems with work. It is also clear from a number of studies, including Tennant (1995) that even those with Good Recovery in Glasgow Outcome Scale terms may continue to have very considerable problems. Tennant observes, the Glasgow Outcome Scale "tends to measure dependency on others". While that is an important and useful thing to measure, it is of course not the whole story.

Apart from nature and severity of injury, the other biological feature of major importance in determining outcome is age. Newcombe (1982) suggests that the Kennard principle may hold for the closed head injured population. This principle, based on recovery in animals, suggests that recovery is better in the young than in the old. Jennett and Teasdale (1981) report a continuous relationship between age and outcome based on studies of patients ranging in age from 5 years to over 75 years. Thus the probability of good outcome or moderate disability declined with increasing age; on the other hand, the probability of vegetative state increased with increasing age. More recently Galbraith (1987) has noted that the elderly are less able to withstand head injury due to decreased cerebral reserves.

On the other hand, Johnson and Rose (1996) cite animal studies to suggest that the immature brain may be especially vulnerable. Two new and as yet unpublished studies furnish some evidence in line with this position although one study is small and the other does contain possible selection biasses. However, the Kennard Principle cannot be accepted with confidence across the whole lifespan: it is possible that in early life, as in later life, there is greater vulnerability. Notwithstanding this, for the adult population age is a significant predictor of general outcome.

b) Neurophysical Sequelae

Jennett & Teasdale (1981) introduce their chapter on the neurophysical sequelae of head injury as follows:

> "Most reports on physical deficits are based on series of patients who have persisting complaints. Those that are the results of an attempt to follow up a whole group of injured patients seldom include a searching neurological examination. How often minor deficits are found, particulary after the less severe injuries, depends on how carefully they are sought. For these various reasons the true frequency of various kinds of deficits after injuries of differing severity is not known." (p271)

Nevertheless, the various deficits which may arise have been documented (Jennett and Teasdale, 1981; Cartlidge & Shaw, 1981; Roberts, 1976; Griffiths, 1983). The possible motor impairments include spasticity, bradykinesia, ataxia, hemiparesis, and tremor. Sensory impairments include loss or diminution of the sense of pain, temperature, position, touch and pressure, along with defects of vision, hearing, smell and taste.

Studies of large series of patients in Glasgow (Jennett and Teasdale, 1981) and Newcastle (Cartlidge & Shaw, 1981) have provided information specified in terms of cranial nerve defects, although the latter series was, on the whole, more mildly injured. As regards cranial nerve 1, Jennett and Teasdale (1981) report anosmia in 7% of head injury admissions, and in the Newcastle series bilateral anosmia was noted in 10% of cases, although in some of these it was attributable to local injury without any necessary involvement of the olfactory nerve (Cartlidge and Shaw, 1981).

Cranial nerve 2, the optic nerve, is usually spared from serious damage, although blurring of vision is common after head injury. In the Newcastle series, only 7 cases (2%) had optic nerve or chiasm injuries, a figure in line with the previous evidence cited (Cartlidge & Shaw, 1981). Damage to the ocular nerves (cranial nerves 3, 4, and 6) has also been recorded but this, too, is relatively uncommon. While

Jennett and Teasdale (1981) note that diplopia is common, they suggest that the problem often lies in the orbit: a small dislocation of the globe or a restriction of its movement may produce an imbalance between the eyes.

Trigeminal and facial nerve injuries have also been recorded but are also rare. In the Newcastle series, 3% of patients had trigeminal nerve lesions and 2% had facial nerve lesions, figures of the same order of magnitude as in previous studies cited (Cartlidge & Shaw, 1981). Jennett and Teasdale (1981) suggest that when associated with a transverse fracture, resulting facial palsy is immediate and complete, but when associated with longitudinal fracture, facial palsy may be delayed and recovery may then occur over a few weeks.

Lesions in the cochleo-vestibular system may occur centrally or peripherally (Jennett and Teasdale, 1981) and audiological tests have shown abnormalities, including hearing loss and tinnitus, in more than half of the large series studied by Toglia & Katinsky (1976). However only 4% of the Newcastle series were identified as having suffered hearing loss as a result of their head injuries (Cartlidge & Shaw, 1981). The functional significance of the Toglia and Katinsky finding remains uncertain. It is presumably an example of 'making silent lesions speak': however, it should not be dismissed from the point of view of possible functional significance. Finally damage to the lower cranial nerves (nerves 9 to 12) is very rare, occurring in closed head injury only where there are extensive basal skull fractures (Cartlidge & Shaw, 1981).

A number of studies have attempted to survey the overall frequency of neurophysical deficits in the head injured population. Some findings from the work of Cartlidge & Shaw (1981) have already been reported. Jennett (1975) found focal signs of brain damage soon after injury in 20% of a large series of patients with compound depressed fracture. Only half of these had deficits at six months. Sixty one percent of patients with acute intra-cranial haematoma had hemiparesis soon after injury: again only half of these still had hemiparesis at 6 months. This study suggested too that cranial nerve dysfunction is common initially, but often resolves.

Roberts (1976) reported on over 300 patients who had been in PTA for more than a week and had also been unconscious. Hemiparesis was the main physical disability in 40% of the sample, although this was often slight, and 25% had no neurological deficit. Jennett et al (1981) found no neurological abnormality in 25% of their series and concluded that mental defects were of greater significance than physical defects. Bond (1976) also reported that social and psychological deficits outweighed physical deficits in significance for severely head injured patients.

However, late traumatic epilepsy is a sequel that can have considerable functional significance. Jennett & Teasdale (1981) note that about 5% of hospital admissions for non-missile head injury will develop late traumatic epilepsy. (Fits occurring in the first week are considered to belong in a separate category). Jennett (1975) reported that of 481 patients with late epilepsy occurring up to four years after injury 27% had their first (late) fit within three months and 56% within a year.

A major study of post traumatic epilepsy is that by Jennett in 1975 in which over 800 patients with traumatic epilepsy following non-missile head injury were studied. More than half of the cases with late epilepsy had onset within the first year, but a quarter had onset 4 years or later after injury. Risk of late epilepsy is increased by the presence of early epilepsy, the presence of a haematoma and the presence of a depressed fracture. Taking these factors into account, and in addition duration of PTA, presence or absence of dural tear or focal signs, Jennett (1975) is able to offer detailed predictions of the percentage risk of late epilepsy developing. For example, in patients with compound depressed fracture but whose PTA is less than 24 hours, who have no dural tear and no early epilepsy, the risk is less than 5%. However, in patients with compound depressed fracture whose PTA is more than 24 hours, and in whom focal signs and early epilepsy are present, the risk is in excess of 60%.

In summary, a wide range of neurophysical sequelae may occur initially following head injury but that many of these resolve leaving only slight residual deficits. However, epilepsy may develop as a late complication, and the probability of this happening can be predicted from certain features of the injury and early course.

c) Cognitive Sequelae

The study of cognitive deficits following head injury extends back to the work of Conkey (1938), and Ruesch (1944). However since the 1970s an extensive literature has built up on the nature and extent of the cognitive sequelae severe blunt head injury. What is offered here is a selective and brief review of the area. As in the previous section, the aim is to set a context for the consideration of psychosocial changes and effects on the family.

i) Intelligence

A series of studies by Brooks and his co-workers demonstrated a degree of impairment in IQ. Brooks and Aughton (1979 a, b) reported on a very severely injured group of 89 patients (median PTA was approximately 14 days). These patients were tested between 1 and 24 months after injury (66 of them within 6 months of injury) and were compared with 30 non head injured controls who were drawn from an orthopaedic clinic. On Raven's measures of verbal and non-verbal intelligence (Raven, 1960; 1962), the head injured patients performed less well than controls, both differences reaching statistical significance. However, the difference was greater in respect of the non-verbal task where the head injured patients scored on average 9 IQ points less than controls, while on the verbal task the difference was only 5 points. Moreover, the non-verbal task showed a striking severity effect whereby the more severe the injury, the lower the IQ; the verbal test did not show this effect. This last observation provides some evidence to support the idea that the non-verbal scores reflect brain damage while not providing such evidence for the verbal scores.

The general conclusions from this study were in accord with a previous study of patients with injuries of similar severity by Mandleberg and Brooks (1975). They had, in addition, shown that the recovery of IQ (assessed this time by the Wechsler Adult Intelligence Scale, 1958) follows a decelerating curve with the final level of recovery being related to severity of injury (as assessed by duration of PTA). There were considerable improvements in mean IQ between 3 and 6 months post injury, but thereafter the gains were modest. In this study the differences between head-injured and control subjects' IQ scores at 4 to 6 months post-injury were 7 points for verbal IQ and 11 points for performance IQ, figures in a similar range to those obtained in the Brooks and Aughton (1979 a, b) study already described. However, at 7 to 12 months after injury (mean 10 months) these differences were only 2 IQ points for both verbal and performance IQ. In a further paper, Brooks and Aughton (1980) reported on 24 head injured patients (again of similar severity) who were compared with 30 orthopaedic controls. At the 12 month follow-up both verbal IQ and non-verbal IQ are virtually the same as the IQ scores obtained by controls.

Impairments in IQ are therefore modest in size, especially by about a year after injury when most recovery has taken place. The evidence suggests, on the whole, that non-verbal IQ is more influenced by brain injury. However, when allowance is made for test error, one may question whether deficits are often large enough to be of clinical importance. Newcombe (1982) suggests that we cannot expect standard IQ tests to provide an adequate reflection of the intellectual consequences of brain damage. She refers back to Hebb's (1945) argument that intelligence comprises, firstly, crystallised knowledge and skills and, secondly, fluid capacities to learn new materials and solve new problems. Newcombe suggests that standard IQ tests tap the former more than the latter and that the IQ test can do no more than provide a framework for interpreting the results of more detailed tests.

Indeed, a recent study (van den Broek & Bradshaw 1994) reports on the use of Raven's Standard Progressive Matrices in combination with a measure of premorbid intellectual level in a sample with brain injury: this test combination was effectively of no value at all in differentiating those with brain injury from control subjects.

ii) Memory and Learning

Although head injury produces deficits in IQ which are often fairly modest, deficits in other aspects of cognition are often very striking. Memory disturbance following head injury is particularly common and has been reviewed by a number of authors (Schacter & Crovitz, 1977; Newcombe 1982; Brooks, 1984).

The first and most striking defects of memory are retrograde amnesia (RA) and post traumatic amnesia (PTA) which have been mentioned in the previous chapter. However the concern here is with more persisting deficits.

One line of research has been the use of well-known psychometric tests to assess head injured patients. Studies of this sort include that of Brooks (1976) in which the Wechsler Memory Scale (1945) was used. The patients studied were on the whole very severely injured (median PTA between 15 and 28 days) and they were assessed within two years of injury. On Forwards Digit Span and accuracy (but not speed) of Mental Control (both very simple tasks), the head injured group did not differ from controls. However, on all other tasks they did significantly less well and the greater the severity of injury (as assessed by PTA duration) the poorer the performance tended to be. The strongest severity effects were on Logical Memory and Associate Learning, two subtests which make greater demands on memory especially when, as here, delayed recall was also tested. Brooks (1976) concluded that these patients had particular difficulty in learning new material, whereas the recall of old information acquired before injury was much more intact.

Lezak (1979) reported similar findings from a study of 24 traumatically brain injured males examined after the return of consciousness and on further occasions up to the third year post trauma. She concluded that these subjects' performance was relatively intact only on the simplest of tasks (digits forwards, and another fairly simple measure of immediate verbal recall). Performance on more complex tasks, including digits backwards, was impaired to a greater extent and showed a lesser degree of improvement.

The particular difficulty these patients have with new learning is widely emphasised in the literature. Indeed, impairment extends to the acquisition of visuo-spatial as well as verbal information whether tested by standard psychometric measures or using experimental paradigms. Newcombe (1982) has argued the need for a more functional and fractionated approach based on the concepts of cognitive psychology. Some efforts to begin this task have already been made.

For example, a verbal free recall paradigm was used (Brooks, 1975) to investigate short term memory (STM) and long term memory (LTM): there was evidence of impaired LTM while STM was spared. This finding was in accord with the studies already mentioned which were based on psychometric measures.

The reasons for failure of LTM may include failure to store or failure to retrieve the to-be-remembered material. Levin et al (1979) addressed this issue using the Bushke Selective Reminding Task (1974). They studied 27 patients whose Glasgow Coma Scale score on admission was 8 or less (i.e. their injuries were "severe" or "very severe") assessing them at a median time post-injury of about 1 year. Storage was defective in 9 of the 27 cases (including all 5 who were "severely disabled" on the Glasgow Outcome Scale); and retrieval was defective in 10 cases (again including all 5 "severely disabled"). The authors caution that the neuropsychological scores in their group were "markedly heterogeneous" (Levin et al. 1979, p.421). In general, conclusions about the deficits found after head injury often need to be qualified by this caveat.

The question of the time course of improvement of memory after head injury has been addressed in a number of studies and is reviewed by Brooks (1984). Brooks concludes that the recovery of memory and learning skills is a more prolonged process than the recovery of other mental functions. In contrast to the near normal levels of performance on IQ tests found by 12 months post-injury, memory continues to be impaired. Recovery may be more prolonged but it is also slower with continuing deficit.

A further and complementary approach to the study of memory has been the work of a group at Cambridge on memory in everyday life. Instead of formal assessment with memory tests they have used questionnaires and checklists to explore the memory failures experienced in the patient's own environment. In the present context, the most relevant of their findings concern the sorts of problems which arise most commonly following severe head injury. These include mislaying things, forgetting to pass on a message, repeating a question or statement, and having difficulty picking up a new skill (Sunderland et al. 1984). These are not necessarily reflected in scores on formal tests which on the whole do not correlate closely with these "everyday life" memory failures (Sunderland et al. 1983).

One possible source of confusion regarding memory arises from the distinction between episodic and semantic memory. This is discussed by Newcombe (1982) and need not be elaborated here except to note that episodic memory concerns "personal experiences and their temporal relations" while semantic memory concerns "the world of objects, properties and relationships" (Newcombe, 1982, p.119). In general, head injured patients have semantic memory which is spared relative to episodic memory: they may remember a great deal of information learned before injury (and in that sense could be said to have a good memory) but have very poor memory for recent events.

In conclusion, memory failures are a significant problem after severe head injury, with deficits being wide ranging and persistent. The difficulty is in learning new information and aspects of both storage and retrieval seem to be implicated, with some variation across individuals both in the nature of the deficit (Levin, 1979) and possibly in the pattern of recovery (McKinlay and Hickox, 1987).

iii) Attention and Mental Speed

A further area of research which is of importance in the present context is sustained attention and mental speed. Gronwall & Sampson (1974), using the Paced Auditory Serial Addition Task and a Choice Reaction Time Task, have concluded that "recently concussed patients" are poorer than controls, and that concussion leads to reduced information processing especially reflected in tasks which require sustained effort.

Van Zomeren & Deelman (1978) have provided good evidence of persisting deficits on four choice visual reaction time 2 years post injury using a sample of 57 males. They obtained significant correlations between performance on this task and a range of variables. Correlations with duration of post traumatic amnesia were of the order of 0.6 ($p<.001$) and correlations with various EEG measures were of the order of 0.4 ($p<.05$). Correlations were also obtained with clinical outcome (memory, concentration, apathy, and social outcome as rated by a neurologist). Later work by the same group (van Zomeren and Brouwer, 1990) emphasises both mental slowness and problems with divided attention (e.g. doing two things at the same time) as common and in some cases an inability to shift attention from one task to the next.

iv) Cognitive Abilities - Conclusions

In conclusion, although disorders of perception, praxis and language may occur (Newcombe, 1982), it is deficits in memory, attention and mental speed which are most characteristic of closed head injury. Such deficits should be borne in mind in examining the broader "psychosocial" sequelae of injury. It is possible that they may underlie at least some of the emotional, behavioural, and social changes to be described in the remainder of this thesis.

CHAPTER 5

EARLY STUDIES OF PSYCHOSOCIAL OUTCOME

The term "psychosocial sequelae" is used here to denote emotional and behavioural changes following injury together with their effects on family, leisure and occupational life.

a) The Importance of Psychosocial Outcome

It has long been observed that emotional and behavioural changes arise following severe head injury. In 1934, Russell reported on a series of 200 head injured patients with a wide range of severity of injury. Some had lost full consciousness for less than one hour, while at the other end of the range were patients who had lost full consciousness for over 72 hours. The distribution appears to have included more of the milder than the more severe cases. They were assessed on average 18 months after injury.

Those who showed "post-concussional symptoms" (which appear to be equated with "some after effects of the injury") lasting for at least 2 months after discharge were identified. The commoner symptoms were headache (in 42% of cases), dizziness (29%), loss of memory or intellectual ability (25%), nervousness (23%), disturbances of behaviour or personality (18%) and sleeplessness (12%). These were much more common than neurophysical disturbances: of these, unilateral deafness (8.5%) was commonest with motor disturbances (3%), diplopia (2%), and other neurophysical disorders much less common.

Symptoms were more common and lasted longer with increasing age: 46% of 10-20 year olds had at least one symptom, whereas 100% of those over 50 years had one symptom or more. Fifty-two percent were back at work within 2 months and duration of "incapacity" (absence from work) was greater in the older patients. Severity of injury (assessed by duration of PTA) also showed some relationship to length of absence from work. However, the most significant conclusion was held to be that a large proportion did return to work: only 7 out of 110 cases had not returned to work after 18 months, 3 of whom had mild injuries and were claiming compensation. Finally, while severity of injury showed some relationship to outcome, presence or absence of skull fracture did not.

A number of other studies, not all so carefully documented as Russell's (1934), have also offered a wide-ranging survey of the spectrum of problems, and in particular the psychosocial problems, that may follow head injury. Denny-Brown (1945) and Guttman (1946), both reported in the mid-1940s on groups of predominantly mild-to-moderate injuries and both concluded that psychogenic factors were important. The latter found head injured patients with chronic symptoms to be very similar in symptomatology and prognosis to neurotic patients, while the former also argued that mild and severe injuries produced similar effects, differing in degree rather than type.

Miller and Stern (1965) reported on 100 cases of severe head injury (mean PTA 18 days) from their medico-legal practice. Assessments were carried out at a mean time post injury of 11 years. Their view was that in the most severely injured cases

> "... personality changes and temperamental disturbances are unequivocal...(and that)...the genuineness of such disablement is unquestionable" (p.225).

Nevertheless, they found overall outcome to be more favourable than they had expected. Only 16 out of 92 patients examined showed psychiatric symptoms, 10 being demented, 4 psychoneurotic and 2 unclassified, one of whom had poor premorbid social adjustment while the other may have simulated disability.

Miller and his co-authors (1965) were on the alert for evidence of simulation, which they were prone to suspect, and it is worth recalling Cartilidge and Shaw's (1981) cautionary note:

> "...in the context of medico-legal examination (symptoms) are apt to be attributed to attempted deception for the basest of motives, yet how often are

> they encountered in every day practice where 'functional overlay' is readily accepted on the basis of anxiety or diminished expectations of performance" (p.153).

In considering the results obtained by Miller and Stern (1965), we must therefore bear in mind not only the atypical population, but the nature of the consultation itself.

Roberts (1976) reports a study by Solch and Schuyra in 1972 in which 308 cases with "severe cerebral injuries" were described. Intellectual and psychiatric impairments were considered the most severe persisting consequences with a general slowing of thought, loss of memory, loss of initiative, and irritability identified as being particularly common and "severe frontal personality change" identified in 1 in 10 cases.

Two further wide-ranging studies provide evidence to support the view that psychosocial changes are common and of major importance following severe head injury. Bond (1975) studied 56 patients with PTA of over 24 hours (52% had PTA longer than 1 month). Assessment was carried out on one occasion between 3 and 24 months post injury, with patients examined on neurophysical, social and mental scales. Family cohesion was particularly vulnerable to memory and personality difficulties while it was fairly resistant to physical handicap. The extent of all forms of disability was related to PTA duration.

Jennett et al (1981) studied 150 cases at between 1 and 14 years post injury. All had severe injuries and mental sequelae were judged to be dominant. Personality change was judged to be present in 2/3 cases and to be the only deficit in 30%.

A number of studies and papers have provided more detailed information on aspects of psychosocial outcome and have noted, too, the burden on relatives. Thus, London (1967) noted that personality change was "one of the most distressing effects of severe cerebral injury", and one which is a great burden to the family.

Fahy et al (1967) found "psychiatric symptoms" in 17 out of 22 severely injured cases, although half the group had suffered no financial disadvantage because of a change in work capacity and post concussional symptoms were discovered in only 3 cases. These authors also observed that patients' accounts were often not reliable:

> "Sensible of their difficulties in the field of intellect, memory, and speech, patients seldom acknowledged temperamental changes, which in turn distressed their families most." (p.477)

All of their severely injured cases had more than 3 days' PTA (mean 37 days) "where this could be assessed" but the admission criterion for the study was that patients needed a burr-hole. Patients who were comatose and did not show and sustain signs of improvement within a short time of admission were subject to burr-hole exploration. The lack of precise definition of terms used in this procedure makes it less exact than use of, for example, the Glasgow Coma Scale (Teasdale & Jennett, 1974) or duration of PTA as an admission criterion for the research.

The precise source of information about the cases studied is also unspecified: the various examinations carried out included standard psychiatric interview conducted "in the presence of suitable informants .... in patient's homes" (Fahy et al. 1967, p.475) with additional information from family doctors, employers, and trade unions. While the range and detail of their enquiry was very admirable, information from patient and spouse is inclined to differ, particularly inasmuch as patients deny emotional and behavioural and, to a lesser extent, cognitive changes which relatives report observing (McKinlay & Brooks, 1984). Knowledge about the exact source of information is therefore important if comparisons are to be made with other studies.

Panting and Merry (1972) studied a group of 30 cases in a rehabilitation setting and reached the following conclusions:

i) There was marked social disturbance which families found it difficult to tolerate.

ii) Families were particularly concerned about outbursts of rage.

iii) Outbursts of rage were particularly severe in patients who showed evidence of premorbid instability.

iv) Husband/wife relationships were more vulnerable than those between parent and child.

v) Divorce occurred in 3 cases, and separation in one.

vi) 60% of relatives were judged to require supportive treatment such as the prescription of tranquillisers.

This study is of importance in drawing attention to the importance of rage outbursts as a source of concern to relatives and in highlighting the particular difficulties for the marital relationship. Its limitation is that it is based on a group of patients in rehabilitation: such patients will have particular problems which have led to referral for rehabilitation, and they cannot therefore be taken as representative of severe head injuries in general.

Thomsen (1974) reported on a follow-up of 50 patients, many of whom have now been followed for as much as 15 years (Thomsen, 1984). This was a group of patients who were very severely injured indeed and although they are described in detail it is not clear if there were precise admission criteria for the study. Amongst other investigations, patients and relatives were both interviewed.

The complaints of the patient were few, although many suffered from loneliness, but changes in behaviour were seldom admitted. For relatives, on the other hand, changes in personality were the greatest source of trouble and the most common changes included irritability, hot temper, aspontaneity, restlessness, emotional regression, emotional lability and stubbornness. Finally, the relationship between single patients and their mothers appeared to be better, on the whole, than that between married patients and their partners: it is suggested that the degree of role change required of spouses in this situation is greater than that required of parents.

Further attention was paid to the family response by Romano (1974). She observed the responses of 13 families to traumatic head injuries suffered by members of the family unit. Although depth or duration of coma or PTA duration are not recorded, it appears that all had sustained severe or very severe injuries and all had been admitted to a rehabilitation unit. On the basis of close observation she identified denial of disability as the most striking feature of these families' response.

A number of examples were given by Romano. Faced with a patient who had emerged from coma but was a changed personality, relatives would sometimes take the view that he was only sleeping and one day would "wake up". Another instance of "denial" was the interpretation placed on post traumatic temper tantrums: these would be viewed as a facet of premorbid personality ("he always did have a temper") instead of being recognised as very obvious changes.

A number of tentative conclusions are suggested by the studies which have been outlined so far:

(1) Changes which may be described by such terms as "emotional/behavioural change", "personality change", or even "psychiatric symptoms" are common (Fahy et al. 1967; Panting and Merry, 1972; Thomsen, 1974; 1984).

(2) These changes are a source of distress to relatives, with husband/wife relationships more vulnerable than parent/child relationships (Panting and Merry, 1972; Thomsen, 1974; 1984).

(3) Patients may lack insight or fail to admit difficulties, an observation made by both Fahy et al (1967) and Thomsen (1974, 1984) and one which had previously been made by Miller & Stern (1965) reporting on a group of patients seen for medico-legal assessment. They noted of such patients that:

> "Their insistence that all is well is a potential source of injustice, unless either a percipient relative or an expert physician is able to show

> that disability is very much more serious than either subjective complaints of superficial observations of performance would suggest".

Kinzel (1968, reported by Roberts, 1976) has also noted that euphoria is a problem in assessing outcome.

(4) Finally, it has been noted that relatives may "deny" changes in the patient (Romano, 1974) while Lezak (1978) has made the related observation that relatives may take some time to realise the full extent of changes in the patient.

However, there are many methodological difficulties which arise in research in this area, and methodological flaws limit the extent to which confidence can be placed in the conclusions of many studies, or generalizations be drawn from them.

b) Methodological Issues

Oddy et al (1978) listed four kinds of methodological limitation which had arisen in previous studies. Firstly, despite the evidence that coma and PTA duration are good prognostic indices, other - sometimes idiosyncratic - criteria have been used to select or describe study populations. Thus Fahy et al (1967) admitted to their study patients who required a burr-hole while others have drawn cases from rehabilitation centres (e.g. Panting & Merry, 1972; Romano, 1974). Not only may such samples be poorly described, one may also question to what extent they are representative of the severely head injured population as a whole.

A second methodological difficulty raised by Oddy et al (1978) is that age distributions have varied widely from one sample to another, which is important since recovery is age related (as discussed in Chapter 2). At this point it is worth adding that studies have also varied in terms of other demographic indices. Parsons and Prigatano (1978) have argued inter alia that educational and socioeconomic level, as well as age and sex, are important variables in neuropsychological research. Oddy's own sample (1978), however, differed from the head injured population as a whole (see Field, 1976) in being younger and of higher social class: thus, 80% of Oddy et al's (1978) sample were under 25 years of age and more cases were from the upper than lower social strata.

A third methodological issue raised by Oddy et al (1978) is that follow-up assessments have been performed at widely differing intervals, not only between but also within studies. For example, Bond's (1976) study included patients assessed between 3 and 24 months post injury while Oddy et al note that follow ups have been carried out between 3 months and 40 years. This, of course, is hardly a criticism, but a factor which needs to be made explicit and borne in mind in comparing studies.

The fourth methodological issue raised by Oddy et al (1978) is that there has been a lack of uniformity in the measures of outcome used: while specialised studies have used measures of cognitive level or psychiatric morbidity, some more general studies are accused of using "vague and overlapping categories" (Oddy et al, 1978, p.611). However, the availability and adoption of such outcome measures as the Glasgow Outcome Scale (Jennett & Bond, 1975) has been doing much to remedy this. As regards more specialised studies of the emotional, behavioural and social sequelae, the lack of uniformity of measures is more defensible. In reviewing studies in this area, Newcombe (1982) notes that:

> "It appears that the emotional changes observed after head injury do not fit into the formal taxonomy of psychiatry" (p.121).

Further, in considering the personality changes which may follow severe head injury, Brooks & McKinlay (1983) note:

> "Even the selection of an appropriate measuring instrument is a major problem here, as there are many personality theories which generate a great variety of measures, but these often seem singularly inappropriate when judged against the clinical realities of the head injury population. For example, many patients may show a lack of insight, or may be unwilling to admit to changes in personality, or may underestimate the significance or the consequence of

such changes." (p.336).

In view of these considerations, it seems inappropriate to use standard psychiatric measures and premature to expect that there will be a uniformity of measures in this area.

However, there are a number of further methodological issues which have been raised by the present author (McKinlay & Brooks, 1984) the first of which it is relevant to raise at this point. The source of information about psychosocial changes resulting from injury was shown to be significant: the accounts patients gave of changes differed from the accounts relatives gave of changes in these same patients. In particular, agreement was generally high as regards sensory and motor impairments: for example, 77% agreed as to whether or not the patient's sight was impaired (e.g. blurring, diplopia) and 85% agreed on impairment of hearing. There was an intermediate level of agreement on questions about memory (65%) and concentration (63%). Agreement was lowest over emotional and behavioural changes: for example, only 60% agreed as to whether or not the patient had become more bad-tempered and only 52% agreed as to whether or not the patient had become more anxious.

These differences in reports were usually in the same direction, with patients denying changes alleged by relatives rather than vice versa. For example, as regards bad temper, there was disagreement in 21 out of 52 cases, and in 18 of the 21 the patient failed to report a change reported by the relative.

These findings are in accord with the observations of other researchers insofar as patients are particularly prone to failure to admit emotional/behavioural changes which relatives report (Fahy et al, 1967; Thomsen, 1974). Such differences make it difficult to interpret studies where it is not explicit whether patients' or relatives' views are being reported.

For example, Levin et al (1979) used a structured interview with patients and "...in most cases a separate interview with at least one family member" (p.416). In a study by Jennett et al, (1981), a neurologist made a "clinical assessment of the degree of personality change from questioning of the patient and a close relative" (p.289). Miller and Stern (1965) state that "a large amount of information was collected from relatives, medical attendants, lawyers and employers." Certainly, the collection of information from a variety of sources represents a worthwhile and thorough approach; however, if the reports of patients and relatives are not reported separately, it must be the case that the researchers have placed their own interpretation on the material they have obtained in order to produce a single version.

c) Main research questions

An outline of the main research questions is now provided, while more detailed discussion of more recent literature and of more detailed questions will be provided alongside analyses of relevant data from the present study.

At the outset, the aim of the present study was to further explore the psychosocial outcome and, in particular, effects on the family in a well documented group of head injured patients from whom generalizations could be drawn about the severely head injured in general. Thus the mode of selection of cases was important and careful description of demographic and clinical features is provided. In addition, assessments were made at set intervals after injury (3, 6 and 12 months post-injury) to permit study of recovery within cases. And, finally, accounts of patients and relatives would be considered separately, with the latter being the main focus of attention. These features of the study would overcome the major methodological difficulties already listed.

In broad terms the questions of interest are about the extent to which psychosocial changes arise after injury, their natural history, and in particular their impact of carers and other family members. It is carers and family members, even today with developing rehabilitation services in the UK and with long-established rehabilitation services in the USA, who very often undertake the sometimes onerous task of providing long-term care and support. The effects of injury upon them, and how such effects are mediated, are important considerations in the design and implementation of rehabilitation services.

In brief, the main questions are:

i) What psychosocial changes in patients are reported by relatives?

ii) To what extent does recovery occur?

iii) What are the effects of the injury on the family and to what extent do these change after injury?

iv) What is the relationship between psychosocial changes and burden on relatives and family members?

v) To what extent may the idea of "burden" be clarified and developed? Is stress on carer closely related to effects on the wider family?

vi) Are there "predictors" of psychosocial outcome and "burden"? The importance of age and severity of injury as regards general outcome has emerged in the literature reviewed so far: to what extent do these influence psychosocial outcome and burden?

CHAPTER 6

METHOD

a) Introduction

Clinical research is often a collaborative process and in this case a team of researchers was involved. The background will be outlined to make clear the relationship between the present author and the research as a whole.

From 1968 onwards, a group headed by Professor Jennett at the Department of Neurosurgery, University of Glasgow studied both outcome of severe head injury and the factors, especially features of early clinical course, which influence outcome. Much of this work is summarized in Jennett and Teasdale's text on head injury (Jennett & Teasdale, 1981).

Professor Bond of the Department of Psychological Medicine, University of Glasgow, contributed to studies of outcome in general and psychiatric sequelae of injury, in particular. Dr Brooks, at one time a Professor in the Department of Psychological Medicine, researched cognitive functioning following severe head injury: a series of studies was published which described recovery of intelligence and memory as well as the relationship between clinical features and such recovery. Reviews by Bond and Brooks, summarizing this work are to be found in texts on head injury (e.g. Rosenthal et al. 1983; Brooks, 1985). Aspects of these three strands of research were discussed in the preceding chapter. A number of these interests coalesced in a project which forms the main basis of this dissertation.

The project was funded, starting in 1976, by the Medical Research Council and the grantholders were Professors Michael Bond (MB) and Neil Brooks (NB) together with William Kenny (WK), at that time Lecturer in Social Work in the Department of Psychological Medicine.

It was proposed to investigate the social and psychological consequences of severe non-missile head injury. In particular it was intended to carry out a detailed examination of the process of mental and social recovery by repeated assessments and to consider the consequences of injury for both the patient and his or her family.

The details of the cognitive assessment need not be described here save to note that measures of intelligence, memory, and language were administered. These provided a continuation of forms of assessment already used in the Department's research and allowed replication and extension of that research. These assessments were carried out at 3, 6 and 12 months after injury and were accompanied by other cognitive measures in an effort to further articulate the nature of the deficits.

As well as exploring cognitive recovery, the project was intended to examine the broad spectrum of psychological and social changes which may follow severe non-missile head injury. The present dissertation deals with aspects of such changes.

Patients - in addition to the cognitive assessment mentioned - were asked to respond to a brief structured interview. This covered a range of symptoms and also whether they had returned to work or expected to do so. A close associate of each patient, usually a relative, was interviewed separately and questioned - on the basis of a structured interview - about a broad range of possible psychological and social changes in the patient and about the effects of these on family life.

Interviews with patients and relatives (or associates) were carried out at 3, 6 and 12 months after injury. (The term "relative" will henceforth be used in this context but is taken to include "close associates").

There were a number of reasons for carrying out a detailed interview with relatives. Firstly, it is conceivable that the cognitive changes which may follow severe injury, especially deficits in memory and attention, may make these patients unreliable informants. Secondly, it has been noted that patients may lack insight, especially into emotional and behavioural changes. Both of these considerations are discussed elsewhere in this dissertation.

The interview schedule used with relatives was to be a modification of the approach used by Grad and Sainsbury (1963) for assessing changes to family life in relation to psychiatric disturbance in a family member. Their approach to assessment involved considering the mental and physical symptoms displayed by the patient, and general changes to family life and to family health. They also considered the effects of the patient on leisure activities, on children in the family, and on the main carer (often the spouse). In addition, they made an overall estimate of the family burden caused by caring for the patient.

The concept of family "burden" had been further refined by Hoenig and Hamilton (1969) in a study of the family life of psychiatric patients which used the Grad and Sainsbury Schedule. They used a three way distinction in conceptualising "burden" as follows:

a) Objective Burden 1 (OB1) referred to effects that the patient's symptoms had on the household, including financial effects and effects on the health of family members.

b) Objective Burden 2 (OB2) referred to illness related changes in the patient which had been observed by the relative.

c) Subjective Burden (SB) was the degree of stress which the relative experienced as a result of OB1 and OB2. This was a rating of psychological stress, and could be divided into SB1 and SB2 denoting stress attributed to OB1 and OB2 respectively.

The work of Grad and Sainsbury (1963), and Hoenig and Hamilton (1969) provided the conceptual framework for the investigation of family burden comprising the psychological and social changes following injury and their effects on family life. The terms "Objective Burden" (taken to mean changes in the patient) and "Subjective Burden" (taken to mean stress on relatives) were adopted from the studies just described and others have followed this distinction, now generally reported as a two-way distinction (e.g. Kreutzer et al 1994 a, b). However, what Hoenig and Hamilton (1969) referred to as "Objective Burden 1" (i.e. effects that the patient's symptoms had on the household, including financial effects and effects on the health of family members) is also of interest. Given how these terms have come to be used, instead of referring to "Objective Burden 1", the term "Family Burden" is used here to denote effects of the injury upon family activities, health, etc.

The researchers initially implementing the project were the present author (WMcK) and David Martinage (DM). Some preliminary pilot work had been carried out by NB and WK with a view to devising questions suitable for the head injured population. WMcK and DM continued this work, conducting open-ended interviews with a sample of relatives in order to obtain as broad a view as possible of the possible changes which follow injury.

In addition, a survey of the literature was conducted to obtain a list of the changes in patients which had been reported following head injury. WMcK was mainly responsible for the psychosocial aspect of the project while DM was mainly concerned with the cognitive aspects. Preparation of data for computer coding was carried out by WMcK (psychosocial data) and DM (cognitive data) and other researchers.

b) The Sample: Selection Criteria and Characteristics

The sample was made up of patients with severe non-missile head injury drawn from the Institute of Neurological Sciences (INS) in Glasgow. INS is a secondary facility accepting patients from throughout the West of Scotland for investigations and treatments not available at the referring hospitals.

As has been noted above, the precise reasons for referral may vary somewhat between doctors and hospitals as well as over time, and therefore a precise description of patient samples is essential and is included in this chapter. Description of the patient sample is in two parts: the first describes the selection criteria for the study; and the second describes the sample thus obtained.

i) Selection Criteria

Age

Age limits of 16 to 60 years were chosen to limit the diversity of the sample in both cognitive and social terms. From a cognitive point of view, the exclusion of children reduced change due to developmental processes and the exclusion of the over 60s kept to a low level the risk that naturally dementing cases would be included.

From the psychosocial point of view, a case could have been made from a narrower age range. The limits 16 to 60 would include young people not yet married or embarked on a career right through to the long-married who were approaching the end of their working life. Nevertheless, an excessively small sample and only narrowly representative sample would have been obtained if we aimed for those with homogeneous social circumstances. The limits 16 to 60 did have the effect of excluding those who were retired and (nearly all) schoolchildren. This meant that most of the sample were of working age.

Sex

A case could be made for restricting the sample to one sex to limit the heterogeneity of the sample. Although it was anticipated that most of the sample would be male, it was decided not to restrict it to males. This would have reduced the numbers and limited the generality of the results.

Marital Status

Similar considerations apply as in the foregoing sections and married, single, and cohabiting were all included.

Informants

It was necessary for psychosocial follow-up that the patient had a close relative or associate to be interviewed. Those who lived alone and were socially isolated could not be included.

Interviewees (or informants) had to be a relative or close associate who bore a major day-to-day responsibility of caring for the patient, or would do so if the patient was not in hospital. If the patient was so well as not to need care, the informant should be someone who would bear such responsibility if the patient were to be ill.

In practice, this meant that the majority of informants were parents or spouses, the latter being taken to include cohabitees. Nearly all informants lived in the same house as the patients and those who did not lived nearby and were in close, usually daily, contact. The nature of the relationship was established by the interviewer at the outset, and if these criteria were not met, a full research interview was not conducted. Where possible the same informant was interviewed at each follow-up, but this did not always prove possible.

Severity of injury

Initially the plan was to select patients with a duration of coma, as defined by the Glasgow Coma Scale (GCS), of at least 6 hours. This would have had the advantage of obtaining the same sample as that in the neurosurgeons' data bank for which 6 hours coma was the selection criterion. However, duration of post-traumatic amnesia (PTA) proved more practicable.

Complete records of the coma duration of patients were not always available. This was because not all primary referring hospitals had used the Glasgow Coma Scale and patients might be transferred to the Institute of Neurological Sciences (INS) hours or even days after injury. Moreover, because INS is an acute unit and is sometimes very busy, some patients were transferred back to referring hospitals very quickly, sometimes also resulting in incomplete scores after transfer from INS. By comparison, an estimate of PTA could be obtained directly by interviewing the patient in nearly all cases.

The criterion of severity of injury chosen was a duration of PTA of 2 days or more. This is greater than Russell's (1971) definition under which "severe" means PTA of 1 day or more. Using 2 days of PTA ensured that only those with unequivocally severe injuries (at least) were admitted but in the event the bulk of the sample had considerably in excess of 2 days of PTA as will be shown later. All the patients in the multi-centre Data Bank of Jennett et al (see Jennett & Teasdale, 1981, p.90), for which 6 hours' coma was the admission criterion, had 2 days or more of PTA (although of course the obverse need not be true).

It is important to note that in considering duration of PTA, both for the Data Bank and for the present study, it was possible for patients to have a lucid interval before lapsing into coma or amnesia.

Nature of Injury

As has been noted, the majority of civilian head injuries are non-missile injuries. Patients with missile wounds, e.g. gunshot, were few in number and were not included in the sample. This was because the underlying pathology of such injuries is different: the pattern of patchy and widespread injury to the brain which characterises non-missile injuries (Adams, 1982) is not characteristic of missile cases (Newcombe, 1982).

However, patients who had depressed skull fracture were also admitted provided, of course, that they met the other criteria for the study including that they had a period of reduced consciousness resulting in at least 2 days of amnesia.

Pre-Existing Damage to the Central Nervous System

Patients with pre-existing damage to the central nervous system were to be excluded, lest the effects of the present injury be confounded by the previous damage. Thus those with pre-existing epilepsy, infection of the central nervous system, cerebro-vascular accident, tumour, degenerative disease, etc., were excluded. A previous head injury resulting in 2 days or more of post-traumatic amnesia was taken as grounds for exclusion.

A further source of pre-existing damage to the brain is alcohol and drug abuse. No known drug abusers were included but to exclude all heavy drinkers or sometime heavy drinkers would have reduced the sample size and the applicability of the findings. Accordingly, patients were not excluded on the grounds of heavy drinking alone, although those known to be frank alcoholics were not included.

Distance from INS

It has already been noted that INS is a regional centre serving the whole West of Scotland stretching from Dumfries and Galloway to the North-West Highlands and Western Isles. The catchment thus stretches approximately 80 miles south of Glasgow and nearly 200 miles to the North and West. It would have been impractical to admit patients from outlying areas to the study, especially when repeated follow-ups were involved. Nevertheless, the great majority of the catchment population live in the Glasgow conurbation: therefore intake was restricted to those within "reasonable" travelling distance (1.5 to 2 hours) and we were able to pay travelling expenses.

ii) Characteristics of the Sample

Subject to the criteria listed above, a sample was obtained from INS. INS is a secondary facility and head injured patients are admitted from a Casualty Department to the Intensive Care Unit (ICU) at INS. Very few cases with significant head injuries did not pass through ICU and while a small number of head injured patients on other INS wards were drawn to our attention, all proved unsuitable for one reason or another. Consecutive admissions to ICU were identified from the ward admission book, and all those with head injuries were considered to see if they met the inclusion criteria. For most of the criteria, this could be determined from the case sheet. PTA was not generally available at this point and a modest number of cases (10-15) subsequently interviewed were found to have a PTA of less than 2 days and were excluded from the study. The characteristics of the sample thus obtained are described below.

Age

Mean age at injury was 35.3 years with a standard deviation of 14.2. Ages ranged from 16 to 60 and a breakdown in bands is given in Appendix 1, Table 1. This shows that the peak age for injury is young adulthood which is in line with previous descriptions of the head injured population.

Sex

There were 45 male (83.3%) and 9 female (16.7%) patients in the sample, approximating to the ratios of 3:1 or 4:1 reported by others for the head injured population.

Marital status

These data are summarised in Table 1.

Interviewees/Informants

As already explained, only those who were in reasonably close contact with the patient were used as informants. Informants had to be those who bore a major responsibility for caring for the patient or would do this if it became necessary. The degree of relationship between informants and relatives is summarised in Table 2. In the majority of cases the same informant was seen at each follow up although this did not always prove practicable. Nearly all informants lived in the same house as the patients, and those who did not were in close contact.

Table 1/

	Number of cases	Percentage of sample
Single	19	35.2
Married/ Cohabiting	32	59.3
Separated/ Divorced	2	2.8
Widowed	1	1.9
Total	54	

TABLE 1
MARITAL STATUS OF SAMPLE

	3m follow-up	6m follow-up	12m follow-up
Spouse/cohabitee	30	30	30
Parent	15	18	17
Other relative/non-relative	9	6	7
Total	54	54	54

TABLE 2
RELATIONSHIP OF INTERVIEWEE/INFORMANT TO PATIENT
(Number of cases at each follow-up).

Severity of injury

Duration of PTA was used as the measure of severity of injury. The minimum PTA for inclusion in the study was 2 days, which meant that all patients studied had (at least) "severe" injury. Over three-quarters of the patients had more than 7 days of PTA, putting them in the "very severe" range (Russell 1971).

	Number of cases	Percentage of sample
Band 1 2-7 days	12	23.1
Band 2 8-14 days	7	13.5
Band 3 15-28 days	14	26.9
Band 4 29-60 days	12	23.1
Band 5 61 days-indefinite	7	13.5
Total	52*	

* 2 cases had missing data on this variable

TABLE 3
DURATION OF POST-TRAUMATIC AMNESIA.
Range 2 days - Indefinite, Median = 21.0 days

Median PTA was 21 days indicating that as a whole the sample was a very severely injured one. Table 3 describes the distribution of PTA. PTA could not be determined in 2 cases. The use of the median as an indicator of central tendency has the advantage of taking into account those cases whose PTA was indefinitely long. However, in later analyses where it is desired to use PTA in parametric analyses, cases of indefinitely long PTA were given a nominal value of 3 months.

Nature of Injury

As has been argued in the first two chapters, the distinctive feature of non-missile head injury is the widespread and patchy nature of the damage to the brain. Diffuse axonal injury, occurring at point of impact, is one possible component of such injury. However, the extent to which it contributes to the totality of all the damage to the brain is likely to vary: as has also been noted, there are other mechanisms by which diffuse damage may occur (e.g. brain swelling, anoxia). In addition, there will be an overlay of more focal damage in some cases, perhaps resulting from depressed fractures, or from haematomas although the latter may also contribute to diffuse damage by producing compression, herniation, etc.

Nevertheless, in view of the varieties of forms of brain damage, which may occur, it is worthwhile considering some other indices. These will also serve to provide a fuller description of the sample. Some further simple data are available for all cases: nearly half the patients were injured in road traffic accidents and Tables 2-5 in Appendix 1 describe cause of injury and summarise the numbers who had haematoma, fracture, and neurosurgical operation. These data show that the sample is a "neurosurgical" one in that there is a high incidence of haematoma and skull fracture.

Pre-existing Damage to the Central Nervous System

The policy of excluding those with previous frank impairment of the CNS has been explained.

Social and geographic background of sample

The sample was restricted to those within 1.5 to 2 hours' travelling distance of INS. The great majority were from the Clydeside conurbation area. Table 4 shows the proportion of the population falling into each social class in the UK, and in the present sample. The sample shows an over-representation of class 5 (unskilled manual workers). Class 3 (skilled manual and clerical workers) is particularly under-represented. The over-representation of the lowest classes applies also when the comparison is made with the general population of the Clydeside conurbation (see McKinlay et al, 1981).

Over representation of the lowest class was also found by Field (1976) although in that study the major under-representation was of classes 1 and 2 rather than class 3. Nevertheless, the social composition of the sample is broadly in line with what would be expected in that the lower classes are over-represented.

To summarise the sample, it may be described in the following terms:

i) Patients were aged between 16 and 60 at injury with a mean age of 35.

ii) Males outnumbered females by 5 to 1.

iii)/

	Number of cases	Percentage of sample	General population*
Class 1	2	3.7	5.6
Class 2	6	11.1	15.0
Class 3	16	29.6	46.5
Class 4	11	20.4	24.7
Class 5	19	35.2	8.3
Total	54		

* UK population at time of data collection

TABLE 4
SOCIAL CLASS OF SAMPLE COMPARED WITH NATIONAL CLASS DISTRIBUTION

iii) Patients had severe non-missile head injuries. The minimum PTA for admission to the study was 2 days; however, the median was 21 days and most patients were "very severely" injured.

iv) Many of the patients had clinical features or complications requiring neurosurgical intervention.

v) The lower social classes were over-represented.

vi) The majority were married or cohabiting.

vii) All informants were in a close relationship to the patient: they bore a major responsibility for care, or would have done so had circumstances required it.

c) Compilation and Administration of Questionnaires and Tests

i) Patient Interview and Assessment

Patients were seen at 3, 6 and 12 months post injury and at each follow-up three sets of measures were administered: a questionnaire to obtain background information and an account of symptoms arising from injury; a psychometric assessment, including measures of IQ, memory, and language; and a number of other cognitive tasks, intended to measure simpler functions, were used in an effort to pinpoint deficits more precisely. Only the first of two of these have any place in the present study.

Patient interview

A structured interview was carried out to collect the following information.

i) Estimates of Retrograde Amnesia (RA) and Post Traumatic Amnesia (PTA).

ii) Whether the patient was left or right handed, and if there had been a change because of injury.

iii) Medical history. These data were sometimes available from the medical record, but not always. Despite the possibility that patients' recall might be imperfect, patients were asked rather than relatives: during piloting it became clear that spouses in particular were often unaware of past medical history.

iv) Current medical management. A list of medicines currently being taken was made: when an appointment letter was sent out, patients were asked to bring medicines with them so that we did not have to rely on their account. Information was also collected about contacts with medical and other health professionals.

v) Symptoms/problems experienced by the patient. Interviewers were careful only to record changes. For example, if a patient reported impairment of hearing, this was only recorded as present if two conditions were met: firstly, the impairment arose after and was attributed to injury, or became markedly worse after injury; and secondly, the impairment was present during the period under survey. At the 3 month post injury interview the survey period was 0-3 months post injury; at 6 months it was 3-6 months; and at 12 months it was 6-12 months.

vi) Employment status. Was the patient working? If so, how well could he cope? If not, what was his expectation of a return to work?

vii) Finally, if the interviewer suspected that the patient was not fully orientated, this was assessed clinically.

Psychometric assessment of the patient

Although cognitive performance is not the primary concern of the present thesis, the cognitive study will be described briefly: the present study draws to a very limited extent on the cognitive data collected.

The psychometric measures used were as follows:

i) Intelligence was assessed using Raven's measures. The Mill Hill Vocabulary Scale (Raven, 1962) was used to assess verbal intelligence and the Standard Progressive Matrices (Raven 1960) to assess non-verbal intelligence. These tasks were used in conjunction with Peck's (1970) conversion tables to provide standard IQs. Raven's measures had been used in previous research in the Department and their continued use made available a large data set. Forms 1 and 2 of the Mill Hill were used alternately for each patient at consecutive follow ups to minimise practice effects and the overall order of administration was counterbalanced to avoid confounding forms of test with time post injury.

ii) Other measures included measures of verbal recall (Logical Memory) (Wechsler, 1945) and visual recall (Rey Figure) (Rey, 1964), and two brief language measures to assess comprehension and fluency, the Token Test, part 5 (De Renzi and Vignolo, 1962) and Word Fluency test (Borkowski et al, 1967).

iii) Other cognitive tasks were also completed by the patient but need not be described here.

ii) Interview With Relative

The interview with a relative (or close associate) of the injured person, was to be the major source of data for the present study. The approach chosen was to interview relatives within the overall conceptual framework of "family burden". As indicated earlier, there are three main aspects of burden, and the inquiry about these was contained in the main questionnaire.

Main questionnaire

The first aspect of the questionnaire devised for this study concerned illness-related changes in the patient, which had been observed by the relative. Items were selected on the basis of a search of the literature and a brief pilot study. In the latter, approximately 15 relatives were interviewed and asked open-ended questions about changes they had observed in the patient. Eighty items were obtained and formed a wide ranging inquiry into changes observed in the patients.

The need for a wide ranging study has already been argued, and the decision to ask about a very broad range of possible changes in the patient meant that sacrifices were made in the depth of enquiry about particular problems. Thus, it would be have been interesting to know more about the severity of problems which the relatives observed. However it would not have been practicable to gather information on the extent as well as the presence of each change in the patient in view of other information we wished to collect and given constraints of time.

The second main aspect of the questionnaire concerned the effects of the patient's symptoms on the household. Relatives were asked about their house and who lived there and about housing difficulties related to injury. They were asked about the patient's progress or otherwise towards resuming employment and about the financial impact injury had upon the household. They were also asked about changes in household routine and who carried out household tasks, about changes in leisure habits, and about changes in the health of family members resulting from injury.

In addition ratings were made by the relatives of the amount of "strain" or "distress" they had experienced. This "subjective burden" (SB) was strain arising because of the injury sustained by the patient. SB was rated using a simple 7 point analogue rating scale. Finally, the questionnaire included demographic items, information about the injury and whether compensation was sought, and some information about the patient before injury.

This questionnaire was used as the basis of a structured interview. Those who administered this questionnaire (BMcK and others in the research team) were briefed in detail as regards the administration of the questionnaire and the interpretation and coding of responses. There were certain standing guidelines.

i) In general, it was intended that interviewers use the questionnaire flexibly. Relatives were often under considerable strain and were bewildered by the changes in their spouse or offspring. Many gave quite a detailed account with little prompting and the interviewer filled in the gaps in their account once they had unburdened themselves.

ii) Much of the questionnaire is concerned with changes in the patient or in domestic circumstances resulting from injury. Interviewers were careful only to record <u>changes</u>. For example, the coding of the item "irritability" was as follows: if the patient had become irritable since injury or had become markedly more irritable since injury this item was recorded as being present. If he was not irritable, or had not become markedly more irritable since injury, the item was recorded as being absent.

iii) The survey period of each interview was as follows. At the 3 months post injury interview, changes which had emerged since injury were recorded. At the 6 month interview, changes were recorded which had emerged at any time since injury and were present between 3 and 6 months post injury. At the 12 month interview, changes were recorded which had emerged at any time since injury and were present between 6 and 12 months post injury.

Other Materials Used During Interviews with Relatives

In addition to responding to the structured interview, relatives completed some further measures. They made ratings of the patient's personality which are the subject of a previous paper (Brooks & McKinlay, 1983) and are not included in the present data analyses.

A measure of the relative's own personality was also taken. It was thought that ability to cope with stress, and therefore the extent of the burden, might be related to aspects of the relative's personality. Neuroticism bears an established relationship to stress-related health problems.

Eysenck and Eysenck have developed the concept of neuroticism: it is one of their three dimensions of personality, each of which is conceptualised as a continuum (Eysenck & Eysenck, 1975). They describe their dimensions in the following terms. The high "neuroticism" individual is anxious, depressed, overly emotional and inclined to over react, in short "a worrier". The other end of this dimension (stability) is characterised by calmness and even-temperedness. Their assessment of personality is completed by the dimensions of extraversion and psychoticism. The typical extravert is gregarious, easy-going and impulsive while the typical introvert is reserved and cautious. High scorers on the psychoticism dimension tend to be solitary, insensitive, and hostile.

The measure of relatives' personality chosen provided estimates of these three dimensions: neuroticism (N), extraversion (E) and psychoticism (P). 15 items were chosen which correlated most highly with the total for their scale. Five items represented each of the three dimensions (N, E, and P). Relatives completed this personality questionnaire (as it applied to themselves) at each follow-up.

Assessment of premorbid status

Information about the patient's premorbid status was collected. This included educational background, employment history, finances, and health together with information on smoking, drinking and whether he/she had been in trouble with the police. This information was usually collected the first time relatives were interviewed. Some were interviewed, to establish contact, within a few days of injury while for others the first interview was 3 months post injury.

A summary of the design with a list of the assessments made at each stage is included in Appendix 1, Table 6.

d) Comments on test and questionnaire administration

The main follow up points were at 3, 6 and 12 months post injury because of previous experience and findings.

Studies of cognitive recovery showed that recovery was more rapid in the first six months after injury than in the second 6 months. For this reason the first two assessments were fairly close together (3 and 6 months post injury) with a 6 month interval to the final assessment.

The possibility of an assessment before 3 months was considered, but rejected for two reasons. Firstly, previous experience had shown that it was difficult to assess many patients on measures such as IQ as soon as 1 month post injury; and since these measures were to be used at 3, 6 and 12 months, the use of different tasks at 1 month would have complicated the design. Secondly, many patients would not have been discharged or would only recently have been discharged at 1 month post injury; whereas, by 3 months, most would have been home for long enough for relatives to have observed changes in them.

The 3, 6, and 12 months follow ups were carried out (as far as possible) within a 4 week "window": at the target dates of 13, 26 and 52 weeks post injury plus or minus 2 weeks in each case.

Two criticisms can be made of this procedure. Firstly, the survey periods are unequal. Thus the 3 and 6 month post injury follow ups cover survey periods of 3 months, whereas the final follow-up covers a 6 month period. This leads to some possible difficulty in interpretation. This is not so much a problem with states (e.g. anxiety) but is more of a problem with events (e.g. violence or fits) which must have more chance of occurring in a longer follow-up period. Of course it could also be said that the first period (0-3 months) is in effect shorter as patients were often in hospital for a good part of the time. These issues are relevant to interpretation of "event" items especially. Nevertheless, the procedure adopted has the advantage of surveying the whole year post injury. It was also felt that it was practically easier to survey the period "since the injury" or "since the last interview" than some other period.

A second criticism, which is made with hindsight, is that anniversary effects may have influenced the 12 month follow up in particular. Anniversary effects have been reported in the literature on bereavement and disasters (e.g. see Brooks & McKinlay 1992) and it is possible that a similar effect occurs where a severe injury has occurred. Any such effect might have been reduced by carrying out the final assessment at 10 or 14 months rather than at 1 year post injury.

A final comment should be made regarding the time allowed for each assessment. It is always important to maintain good rapport with subjects if their full co-operation is to be obtained. It is especially important in a sequential follow up that the goodwill of subjects is retained if they are to continue to attend.

e) Reliability

The conceptual basis of the structured interviews with relatives, which form the mainstay of the present study, was the work of Grad and Sainsbury (1963) and Hoenig and Hamilton (1969). As explained, using the concept of burden as a framework, a set of questions of relevant to the head injured was produced. The questionnaire is therefore new in detail if not in approach and its reliability and validity require to be established.

A preliminary reliability study was carried out by two of the principal investigators prior to the main project starting. A pilot version of the questionnaire used in the main study was used. NB and WK each interviewed 10 relatives with the other present. Disagreement between NB and WK only occurred on items where the degree of change in the patient had to be rated rather than the presence/absence of change.

There is therefore simple consensual agreement although that is a less stringent test of reliability than to compare two separate interviews. Moreover, the questionnaire underwent revision between pilot and final versions and so conclusions reached about the pilot version need not apply to further items in the final version.

Carmines and Zeller (1979) in a monograph on reliability and validity, discuss various methods of assessing reliability. Some of these are unsuited to the present questionnaire: thus, the alternative form, split halves, and internal consistency methods all apply to situations in which each item contributes to a total score. This is not the case in the present study: the questionnaire is not intended to measure any construct such as "intelligence" or "neurosis" but is rather an inquiry into changes which have occurred in the patient, in the household, and in family life. A further method of estimating reliability is the test-retest method, and this method is most appropriate in the present circumstances.

Carmines and Zeller mention two problems with the test-retest method. Firstly, the phenomenon being measured may change, and it is probable that the longer the test-retest interval the more likely is such change. This could lead to an underestimation of reliability by interpreting true change as measurement instability. Secondly, the measurement taken at time 2 may be influenced by that taken at time 1: the interviewee may be sensitized to the subject under investigation by being asked about it leading to a "real" change in how the topic is perceived; or the interviewee may remember the responses given on the previous occasion and be inclined to repeat them. Despite these limitations, the test-retest method, with different interviewers conducting separate interviews, would seem to offer a more rigorous test of the reliability of the questionnaire than that provided by the pilot study.

A small test-retest study was therefore carried out. The main study sample was not used so as not unduly to stretch the goodwill of those participating. Instead, patients who had been referred to the psychology service at the Department of Clinical Neurosciences at the Western General Hospital in Edinburgh were studied. Since they were to be assessed anyway, all that was required of them was one further assessment 1 to 2 weeks later. We explained that we wished to compare the results recorded by different researchers.

A test-retest interval of around 1 to 2 weeks was chosen, bearing in mind that the longer the interval the more chance of real change occurring, and the shorter the more risk of memory playing a part. 12 cases were recruited and 9 retested in this way. The exercise is described in Appendix 2. These cases provided a reasonable range in terms of demographics and severity of injury, although they are somewhat more severe than the group studied in this thesis.

Data are only available for some items, but available reliabilities are at a level of kappa of .73 or higher except for three items. These are "impatience" (kappa .50), "expressive language problem" (e.g.word finding) (kappa .36) and "poor concentration" (kappa -.17).

Bearing in mind the previous exercise which found good consensual agreement, for the most part the available reliability data are reassuring. However, this is an area in which there remain few purpose-designed and accepted measures and indeed the reliability exercise described in Appendix 2 is in part towards the development of a refined version of this present questionnaire with methods to extract valid summary scores.

f) Validity

Validity is the extent to which any measuring instrument measures what it is supposed to measure. More precisely, it is not the test itself which is valid or invalid, but the inferences which may be drawn from it. For example, as regards a test of arithmetic, the question would arise of whether it was valid to draw inferences about the subject's general arithmetic ability from test performance. Similarly, as regards a personality test, the question would arise of whether inferences about aspects of the subject's attitudes and behaviour would be drawn from the test scores.

In the present study, the main inquiry is not measurement of ability, personality, or indeed any hypothesized construct. Most of the questions are intended to elicit descriptions, mostly of changes observed in the patient following injury and changes in family circumstances.

Several approaches to assessing validity have been proposed and a discussion of the topic is provided by Carmines and Zeller (1979). Three main types of validity are proposed.

The first, content validity, "depends on the extent to which an empirical measurement reflects a specific domain of content" (p.20). For example, a test of arithmetic must include subtraction, multiplication, and division as well as addition. However, the "domain of content" of most social science measures is less easy to specify, and therefore there exists the suggestion that content validity shades into "face" validity in which a test is judged by what it "looks like". Certainly, the questionnaires used in the present study appear (to this author) to have face validity. Most questionnaire items are direct questions which are intended to elicit straightforward descriptions.

However, while the apparent relevance or face validity of a measure may well be important in gaining acceptance from interviewees, there is no agreed method of quantifying content or face validity. Apparent validity of this sort is widely held not to be sufficient.

A second approach to validation is criterion or external validation. Here the measure under scrutiny is examined in relation to some other measure or event whose validity is not in doubt. As regards the present study, no existing questionnaire was appropriate "as it stood" although an existing framework was adapted (Grad & Sainsbury, 1963; Hoenig & Hamilton, 1969). In the absence of an established measure, the criterion approach to validity could not be used. It is not unusual for criterion validity to be an impractical approach: Carmines and Zeller conclude that:

> "criterion validation procedures have rather limited usefulness in the social sciences for the simple reason that, in many situations, there are no criteria against which the measure can be reasonably evaluated" (1979, p.19-20).

A third approach is construct validity. Carmines and Zeller suggest that construct validation is "theory-laden":

> "....it is impossible to 'validate' a measure of a concept .... unless there exists a theoretical network .... to generate .... predictions which, in turn, lead directly to empirical tests involving measures of the concept." (1979, p23).

However, the present study belongs to an area of research which lacks theoretical formulations. Research is still at the stage of providing a basic description of the sequelae of injury and simple methods of establishing validity are inapplicable.

However, three arguments can be advanced to support the view that the questionnaire and rating measures used have reasonable validity. Firstly, the measures are not completely novel but are adapted from existing measures, for which there is evidence of reasonable validity. Thus the main questionnaire used the "burden" framework proposed by Grad and Sainsbury (1963) and Hoenig and Hamilton (1969) who provided evidence for the validity of their approach. The ratings of the patient's personality made by relatives were made on 5 point rating scales: a good deal of research has appeared on the reliability and validity of such scales which suggests they have value (see Brooks and McKinlay 1983). The measure of the relative's own personality was on a scale derived from the work of the Eysencks (1975).

A second argument for the validity of the measures used is that they were well understood by relatives and they "look" valid. Much of the material elicited from relatives and all the interview data from patients consist of simple descriptions of changes in the patient. Their relevance is clear to interviewees, and no theoretical construct is inferred from them.

Thirdly, there is the question of how well the results of this study form a consistent pattern with the previous literature and with other contemporary studies. Such an approach is essential in researching a new area. The topic of the validity of the questionnaires and ratings is therefore bound up with the extent to which the present findings are consistent with others' findings and to the extent that results are surprising in relation to existing literature, it will be necessary to consider whether measurement issues are involved.

The validity of the standard measures of intelligence, memory, language and the Eysenck personality items has already been well documented and need not receive further attention here.

CHAPTER 7

SEQUENTIAL FOLLOW-UP STUDY

The frequency of the various changes in the patients, as reported by relatives, was calculated for each follow-up time. Table 5 shows the frequency of the most commonly reported changes. All changes ever reported by 30% or more of respondents are included in this set of tables. The items are arranged in descending order of frequency at the 12 month follow-up.

Significance of changes between three and twelve month follow-ups was tested. Initially the non-parametric McNemar test was used as this is especially suitable for two related samples and for dichotomous (yes/no) data (Frude, 1987). However, in later analyses of similar data it was necessary to apply covarying procedures not available with non-parametric statistics. To achieve consistency of approach, parametric statistics have been used throughout and paired t-tests were used to compare the frequency of symptoms between three and twelve month post-injury follow-ups. However, not all of the assumptions for this test are strictly met and due caution will be applied in the interpretation of these results. The fourth column indicates those variables which showed change significant at the 5% level at least together with an indication of whether the number reporting was up "+" or down "-" between 3 and 12 month follow-ups. The entry "ns" in the column means p of .05 or greater. Significance is two-tailed.

TABLE 5

SUMMARY OF MOST FREQUENT CHANGES (AS REPORTED BY RELATIVES) AT 3, 6, AND 12 MONTHS POST-INJURY

	(percentage reporting)			
	3	**6**	**12**	**change**
IMPATIENCE	59.6	63.0	70.4	ns
IRRITABILITY	64.2	68.5	70.4	ns
TIREDNESS	84.0	69.8	70.4	ns
POOR MEMORY	72.2	58.5	68.5	ns
EASILY ANGERED	49.1	57.4	66.7	+ $p<.05$
SLOWNESS (PHYSICAL)	86.0	68.5	66.7	− $p<.05$
MOOD CHANGES	32.1	37.0	61.1	+ $p<.001$
PERSONALITY CHANGE	48.1	57.4	59.3	ns
TENSE/ANXIOUS	56.0	64.8	57.4	ns
DEPRESSED	56.6	50.9	56.6	ns
HEADACHES	54.9	45.3	53.7	ns
CHANGES IN SEX LIFE	50.0	48.3	46.7	ns
EASILY AFFECTED BY ALCOHOL	26.8	32.6	46.0	+ $p<.05$
INTOLERANCE OF NOISE	46.8	40.7	45.3	ns
RESTLESS/WANDERING	37.7	44.4	44.4	ns
CHILDISH BEHAVIOUR	34.0	33.3	44.4	ns
SIGHT PROBLEM	53.8	46.2	42.6	ns

Table continued/

	(percentage reporting)			
	3	6	12	change
EXPRESSIVE LANGUAGE PROBLEM	46.3	42.6	42.6	ns
POOR SENSE OF BALANCE	48.0	38.9	40.7	ns
POOR CONCENTRATION	40.4	37.7	39.6	ns
ATTITUDE TO SEX CHANGED	40.9	37.5	38.5	ns
DEMANDS ATTENTION	34.0	35.2	37.0	ns
SUSPICIOUS/MISTRUSTFUL	22.9	22.6	37.0	+ $p<.05$
DIZZY SPELLS	25.0	25.9	35.2	ns
WEAKNESS - ARM(S)	38.9	31.5	33.3	ns
REFUSAL TO ADMIT DIFFICULTIES	23.5	24.5	33.3	ns
WORRIES ABOUT FUTURE	42.3	37.0	32.1	ns
SPEECH ARTICULATION PROBLEM	33.3	25.9	29.6	ns
WEAKNESS - LEG(S)	37.0	35.2	27.8	ns
EXCESSIVE TALKING	31.9	24.5	25.9	ns
EXCESSIVE SMOKING	29.8	33.3	24.5	ns

In the present study, the most frequently reported changes in the patient were mental rather than physical. Changes in the patient such as slowness, tiredness, irritability, and poor memory were reported in a large proportion of cases. It can be seen from Table 5 that there is relatively little change during the first year. Only five of the items in the table, which includes all items ever reported in more than 30% of cases, show a significant change over time. (The first three items in Table 5 which showed a significant change did so on both McNemar test and Paired t-test, while the other two did so only on the latter test).

The full list of percentages by item is given for all the principal items Appendix 1, Table 7. By and large, the group made a good recovery from the point of view of basic physical mobility: 91% were independently mobile by 6 months post-injury and remained so with only two cases confined to a wheelchair and a further three cases requiring to use a stick or crutch. This, of course, is an admittedly simple measure of physical status but nevertheless the point is made that this is not a group which has obvious physical disability or is wheelchair-bound on the whole. More subtle physical deficits were, however, by no means infrequent and, for example, 39% reported weakness of an arm or arms at 3 months falling to 33% at 12 months.

As regards sensory problems, just over half (54%) of relatives reported that the patient had a problem with vision 3 months post-injury falling to 43% by 12 months, although none of the other sensory problems were reported in more than a fifth of the sample at any follow-up time.

As regards subjective symptoms such as problems with balance, dizziness, headaches, and so on, these tended to be fairly frequent. Problems with balance arose in 49% of cases at 3 months, falling to 41% by 12 months. The incidence of late epilepsy, not surprisingly, rose over the year from 5.6% at 3 months to 14.8% at 12 months. Being slowed down physically was particularly frequent with 86% of relatives observing this at 3 months falling to 67% by 12 months and tiredness was also very common (84% at 3 months and 70% at 12 months).

As in previous studies, changes in the emotional and behavioural area were particularly common: for example, irritability was reported in 64% at 3 months and 70% at 12 months, while the incidence of an overall change in personality was 48% at 3 months and 59% at 12 months. Caution, however, is needed about reading too much into these changes in percentages: as Table 5 shows, only five of the items in the Table changed to a statistically significant extent between 3 and 12 months.

Given the large number of individual items, summary items were calculated, each representing the number of problems in the area reported in each case. In devising these summary variables, an attempt was made to follow distinctions which are made in the literature and in clinical practice. Various quantitative approaches to categorisation of items were considered. However, factor analytical approaches were considered unsatisfactory because of the ratio of number of subjects to number of items (in excess of 90 symptom-type items for 55 subjects).

Another possibility was the use of clustering approaches. These were investigated at some length. These are potentially useful in eliminating items which behave in a very similar fashion. However, there is an absence of widely-agreed criteria for the extent of association between items which would merit the exclusion of one (Afifi and Clark, 1990). Moreover, analyses showed that the removal of an item leads to a reformation of the cluster, often with a different pair of items now apparently behaving extremely similarly. This would sometimes lead, if it were to be followed, to the exclusion of one of a pair of items, both of which would be of considerable clinical interest in view of the literature. Therefore, this approach was in the end given up and the categories used are a refinement of those in the McKinlay at el (1981) paper (which is appended), and are again based on experience and literature rather than on a single operationalised procedure.

The frequency of these summary variables was as follows. Table 6 shows physical, sensory, and self-care variables. Overall, physical items were summed to give a simple scale reflecting the number of items out of the total which individuals reported. This group did show overall a significant decline, albeit at only the 5% significance level. Of the four items used in this group, all four showed a decline from 3 months to 12 months. As regards the sensory items (Table 6), only two of the four showed a decline, the other two showing a rise over the period. Overall, the composite variable did not show any significant change over time.

As regards self-care (Table 6), although there was no overall significant change, 6 of the 7 items which made up this grouping showed a decline from 3 to 12 months with one showing an increase, albeit that all of these changes were statistically insignificant.

Table 7 shows "subjective" changes: the most frequent were tiredness and slowness as already mentioned, followed by headaches and poor sense of balance. Although the overall variable showed no change, five of the items were less frequent at 12 months than at 3 with two showing an increase. As regards emotional changes (Table 7), again the composite variable showed no significant change. The most commonly reported emotional changes were impatience and irritability, both 70% at 12 months and mood changes which was reported in 61% at 12 months, this being one of the few items which showed a significant change between 3 and 12 months. Overall, six of the nine items in this area became more common with the passage of time.

TABLE 6
NUMBER OF PHYSICAL, SENSORY, AND SELF-CARE ITEMS REPORTED AT EACH FOLLOW-UP (reported by relatives).

PHYSICAL (4 items): Weakness or restricted movement in arm(s) or leg(s).
SENSORY (4 items): Problems with sight, hearing, sense of taste, or sense of smell.
SELF-CARE (7 items): Problems with washing/bathing, lack of concern with cleanliness, enuresis, clumsiness, need for care, need for supervision indoors/outdoors.

VARIABLE	3 mth	6 mth	12 mth	Significance of change *
PHYSICAL	3.0	2.5	2.1	Overall p<.05; no two groups differed significantly
SENSORY	2.1	1.8	1.9	ns
SELF-CARE	1.9	1.5	1.5	ns

All scores are scaled as if out of 10 for comparison.
* Overall significance of change assessed by one-way analysis of variance, followed up where p<.05 by Bonferroni tests for multiple comparisons to try to determine where the significance lay.

TABLE 7
NUMBER OF SUBJECTIVE AND EMOTIONAL ITEMS REPORTED AT EACH FOLLOW-UP (reported by relatives).

SUBJECTIVE (7 items): These "subjective" symptoms to some extent overlap with late "post-concussional" symptoms: balance, dizziness, headaches, intolerance of noise, tiredness, slowness, sleep disturbance.
EMOTIONAL (9 items): This variable includes items which reflect poor control of anger and also poor regulation of mood, groups which would be very hard to disentangle. Thus tension/anxiety, demanding attention, impatience, irritability, poor temper control, loss of interests, mood changes, depressed mood, and worrying about the future go to make up this variable.

VARIABLE	3 mth	6 mth	12 mth	Significance of change *
SUBJECTIVE	4.8	4.4	4.8	ns
EMOTIONAL	4.5	4.9	5.3	ns

All scores are scaled as if out of 10 for comparison.
* Significance of change assessed by one-way analysis of variance.

TABLE 8
NUMBER OF SPEECH/LANGUAGE AND COGNITIVE ITEMS REPORTED AT EACH FOLLOW-UP (reported by relatives).

SPEECH/LANGUAGE (5 items): Problems with articulation, expressive language, conversing, understanding direct instruction, and following conversation.
COGNITIVE (2 items): This variable is made up of only two items, but key items - problems with memory or concentration.

VARIABLE	3 mth	6 mth	12 mth	Significance of change *
SPEECH/ LANGUAGE	2.4	2.3	2.0	ns
COGNITIVE	5.6	4.7	5.4	ns

All scores are scaled as if out of 10 for comparison.
* Significance of change assessed by one-way analysis of variance.

TABLE 9
NUMBER OF POOR SOCIAL BEHAVIOUR, "RIGID" BEHAVIOUR, AND VIOLENCE ITEMS REPORTED AT EACH FOLLOW-UP (reported by relatives).

VIOLENCE (3 items): Threats of violence, actual violence, trouble with the law.
"RIGID" BEHAVIOUR (4 items): Routine-bound, suspicious, bossy, or nosey behaviour.
POOR SOCIAL BEHAVIOUR (4 items): Excessive talking, avoiding company, withdrawing, behaving badly in company.

VARIABLE	3 mth	6 mth	12 mth	Significance of change *
VIOLENCE	0.8	0.8	1.1	ns
"RIGID" BEHAVIOUR	1.6	1.5	2.2	ns
POOR SOCIAL BEHAVIOUR	1.5	1.9	2.1	ns

All scores are scaled as if out of 10 for comparison.
* Significance of change assessed by one-way analysis of variance.

Speech and language changes (Table 8) included problems with articulation, expressive language, conversing, understanding direct instruction and following conversation. The first two of these were by far the most common never being found in less than a quarter of the sample at any follow-up, whereas the last three were relatively infrequent, with none exceeding 10% by 12 months. All five of the items in this area showed some degree of decline between 3 and 12 months, although overall the extent of this was not sufficient for the change to be significant. Cognitive changes (Table 8) likewise showed some decline but both memory and concentration problems were, as would be expected, very common and at a year: 68% still had reported memory problems and 40% problems with concentration.

In previous analyses (McKinlay et al, 1981), a range of behavioural changes were grouped together but further experience suggests that these might reasonably be separated and three groupings have been made. The first of these deals with items to do with violence, in particular threats of violence, actual violence and trouble with the law. A number of further items had been included in the study which were to do with threats of and physical violence after drinking, but inspection of the data revealed that these behaviours after drinking were simply a subset of the main problem with some of those prone to violence doing so after drinking while others did not need alcohol to lead to such behaviour. The data relating to the effects of alcohol were therefore not reported here but simply those which reflect the overall incidence of threats of and physical violence.

A caution needs to be entered in interpreting such data. Throughout the reporting of changes in the patient, a request was made to report only items which appeared de novo or which were markedly worse after injury. Therefore changes which had not been present before injury but which were present between injury and 3 months post-injury were entered as present at the 3 month follow-up. Likewise, problems which had not been present before injury and were still present during the 3-6 month period were entered at the 6 month follow-up. Further, changes which had not been present before injury but which were now present or markedly worse are entered between 6 and 12 months are entered as present at the 12 month follow-up. There is therefore an inequality in the follow-up times used. This is unlikely to be of real importance as regards things like tension and anxiety which refer to ongoing states. On the other hand, where discrete events occur such as acts of violence, the fact there is a longer survey period prior to the 12 month follow-up might artificially inflate problems at this time. (It would, of course, have been possible to collapse the 3 and 6 month follow-ups if direct comparisons between these periods were of importance, but this was not felt to be of sufficient interest to be necessary).

Threats or gestures of violence were not particularly uncommon arising in almost a fifth of cases where they had reportedly not been present before injury, with actual violence reported in 7.7% of cases up to 3 months and 11.3% at the 12 month follow-up. However, the overall incidence did not significantly rise in terms of the summary variable (Table 9).

The second grouping was, what is here termed, rigid behaviour (Table 9) and which is a tendency to be overly dependent on routine, to be rather suspicious and interfering. Four items made up this grouping, the most common being a tendency to be suspicious and mistrustful (37% at 12 months). Overall, however, there was no significant change in the frequency of items in this area.

Lastly, poor social behaviour (Table 9) was considered on the basis of grouping items to do with excessive talking, avoiding company, entirely withdrawing from company, or behaving inappropriately in company. Both items to do with withdrawing from company showed some increase, although not statistically significant, although excessive talking declined. Overall, this item also did not show a significant change over time.

Two further analyses were carried out in relation to the question of whether there is significant change over time. Firstly, the total set of symptoms which went to make up the summary variables described in Tables 6 to 9 was considered. A total of 49 individual items had been used and the number of these present in each case was totalled. At the 3 month follow-up, an average of 14.6 items were reported (standard deviation 7.9), while at 6 months the figures were 13.9 (s.d. 8.2), and at 12 months 14.9 (s.d. 8.3). It is clear that there is no overall change and one-way analysis of variance yielded no significant effect.

However, it has been reported (e.g. McKinlay and Brooks, 1984) that some variables become much more frequent and some less frequent over time, and there has been a suspicion that it is those items which relate to emotional and behavioural adjustment which are most prone to show an increase. Accordingly, those summary variables most directly related to such adjustment were grouped together (i.e. "Emotional" change, "Violence", "Rigid behaviour", and "Poor social behaviour"). The 20 items which make up these variables were grouped to form an Adjustment variable, while the remaining 29 items which form the "Physical", "Sensory", "Self-care", "Subjective", "Speech/ Language" and "Cognitive" variables were grouped to form a Physical/Subjective/Cognitive variable.

The number of items from the Physical/Subjective/Cognitive variable which were reported were as follows. At 3 months, an average of 9.1 items were reported (standard deviation 4.6), while the figures for 6 months were 7.9 (s.d. 5.1), and for 12 months 8.1 (s.d. 5.0). The one-way analysis of variance failed to reach the 5% significance level. The number of items from the Adjustment variable which were reported were as follows. At 3 months, an average of 5.6 items were reported (standard deviation 4.2), while the figures for 6 months were 6.0 (s.d. 4.3), and for 12 months 6.8 (s.d. 4.3). The one-way analysis of variance just reached significance (p=.049) but Bonferroni tests did not show any group differences.

The next topic to be considered was the effect of such changes on the carers and upon the family activities, health and so on. Following previous research as described in the Method, it had been decided to refer to the amount of stress or strain reported by relatives on a simple analog scale as "subjective burden". The degree of disruption to the family, effects on carer and family health and so on was now designated "family burden". The subjective burden rating was made on a 7-point scale from 0=no stress to 6=severe stress with a mid-point of 3 marked as moderate stress. The degree of stress reported by relatives is shown in Table 10 and does not show any significant change over time.

The "family burden" was made up of items to do with disruption to family activities and health. This is explored more fully in the next chapter in a study which more explicitly addressed these aspects of burden.

TABLE 10
SUBJECTIVE BURDEN - i.e. RATING OF STRESS - BY RELATIVES AT EACH FOLLOW-UP.

This rating reflects the degree of stress that relatives felt they themselves were suffering as a result of how the injury had affected the patient.

This was rated on a 7 point scale from 0 (no stress) to 7 (severe stress) with a midpoint of 3 marked as moderate stress.

VARIABLE	3 mth	6 mth	12 mth	Significance of change *
SUBJECTIVE BURDEN RATING	2.5	2.4	2.5	ns

* Significance of change assessed by one-way analysis of variance.

However, in the present study the available information indicates that there were frequent problems in this area. The carer reported that his/her health had been adversely affected in 31%, 29%, and 42% at successive follow-ups. Adverse effect on any children in the household were reported in 27%, 32%, and 22% of applicable cases at successive follow-ups. (On the same analyses as with changes in the patient, the comparison of 3 and 12 month level does not show significant change).

Lastly as regards burden, the relationship between subjective burden and changes in the patient is summarized in Table 11 and receives comment in the Discussion.

TABLE 11/

TABLE 11

CORRELATION BETWEEN SUMMARY VARIABLES (reported by relatives) AND RELATIVES' SUBJECTIVE BURDEN AT EACH FOLLOW-UP.

Each results cell shows:

(1) Pearson correlation (2) N of cases in the computation
(3) Two-tailed significance grouped as:
NS = not significant p<.05 p<.01 p<.001

(1)
(2) (3)

For ease of reading, where correlations are at the 1% or 0.1% levels of significance they are printed in bold.

VARIABLE	3 mth	6 mth	12 mth
PHYSICAL	.32 n=51 p<.05	.22 n=53 NS	.31 n=54 p<.05
SENSORY	.17 n=51 NS	.12 n=53 NS	.29 n=54 p<.05
SELF-CARE	**.50** **n=51 p<.001**	**.51** **n=53 p<.001**	.34 n=54 p<.05
SUBJECTIVE	.14 n=51 NS	**.53** **n=53 p<.001**	**.47** **n=54 p<.001**
EMOTIONAL	**.48** **n=51 p<.001**	**.54** **n=53 p<.001**	**.58** **n=54 p<.001**
SPEECH/LANGUAGE	.34 n=51 p<.05	**.43** **n=53 p<.01**	**.37** **n=54 p<.01**
COGNITIVE	.33 n=51 p<.05	**.47** **n=53 p<.001**	**.39** **n=54 p<.01**
VIOLENCE	.23 n=51 NS	**.49** **n=53 p<.001**	**.36** **n=54 p<.01**
OBSESSIONAL BEHAVIOUR	.19 n=51 NS	**.39** **n=53 p<.01**	**.51** **n=54 p<.001**
POOR SOCIAL BEHAVIOUR	**.50** **n=51 p<.001**	**.48** **n=53 p<.001**	**.43** **n=54 p<.01**

There are two further matters which will be described for completeness. Firstly, an attempt was made to assess the extent of cognitive impairment. Had this proved successful, the extent of estimated impairment would have been considered as a possible contributor to burden.

Nowadays, there are measures available which are intended to give an estimate of premorbid intellectual level, in particular the National Adult Reading Test (Nelson, 1982). This measure provides an assessment of an ability which is highly correlated to intelligence yet is relatively robust to the effects of brain injury. The test thereby provides an indication of premorbid ability. It does so by measuring the ability to pronounce irregular words. Clinically one would not rely on this measure if there was significant language disturbance.

In the present study, a few formal psychometric measures were used including the Mill Hill Vocabulary Scale (Raven, 1962) and Standard Progressive Matrices (Raven, 1960). The Mill Hill Scale assesses verbal ability by means of a vocabulary test. Vocabulary is relatively robust to the effects of brain injury, representing a "crystallised" ability, whereas the Matrices is more vulnerable, representing a fluid ability. (It should be added however that with the benefit of hindsight it may be said that the Matrices is not a sensitive test of the intellectual deficits which may follow brain injury but that timed tests, e.g. many Wechsler Adult Intelligence Scale subtests (Wechsler, 1958), are better). Given that the Mill Hill may reasonably be expected to be the most robust of the measures used, it was chosen as a possible index of premorbid ability.

An attempt was made to remove cases who had a current language impairment. There were 4 language scores available, those for the Token Test part 5 (De Renzi and Vignolo, 1962) and for the three trials of the Word Fluency Test (Borkowski et al, 1967). Using previously published norms (Brooks & Aughton, 1979a, 1979b), the means and standard deviations of each measure were identified. Then cases who fell more than two standard deviations below the mean were identified. The number of cases falling more than two standard deviations below the mean on each measure was as follows: Token Test - 9 cases; Word Fluency trial 1 (category) - 9 cases; Word Fluency trial 2 (easy letter) - 11 cases; Word Fluency trial 3 (hard letter) - 9 cases. A total of 10 individuals fell below these cut-offs on 2 or more measures (with 7 cases coming below criterion on only 1 measure). It was decided to take these 10 cases out of the analyses in which Mill Hill score would be used as a proxy for premorbid ability.

The 44 remaining cases had a mean Mill Hill Verbal IQ (derived using Peck's (1970) norms) of 93.9 (standard deviation 9.6). Their mean Matrices IQ (derived using the same norms) was 102.4 (s.d. 17.3). It was therefore clear, given the lower average score on the supposedly more robust measure, that the Mill Hill was not in fact providing a useable index of premorbid ability.

A possible explanation lies in the social class distribution of this population. As has been noted earlier, there is a very marked over-representation of the lower social classes in the sample, and there were certainly individuals who had left school early, with limited education, and did poorly on the Mill Hill but who obtained high Matrices scores. This line of enquiry, attempting to assess extent of impairment by taking into account previous level of ability, was therefore pursued no further with the present data set.

The second further matter concerns the possible influences of two variables on the results obtained. The first possible influence is injury severity. In studies of brain injury outcome it is important to keep in mind the issue of injury severity. Might it simply be the case that the "effects" found are a reflection of severity, and that the more severely injured individuals have poorer outcomes and place more burden on their families? In relation to the present data set, this issue has already received attention (McKinlay et al, 1981 - reprint appended). In this paper, duration of Post Traumatic Amnesia (PTA) was used as a measure of injury severity. There was a significant tendency ($p<.001$) for burden to be associated with PTA at the first follow-up, 3 months post-injury. The relationship was weaker at 6 months post-injury ($p<.05$), and not statistically significant at 12 months. This matter receives further attention in the next chapter.

The other possible influence to be considered was relatives' personality. This received careful consideration in another previous paper (McKinlay & Brooks, 1984 - reprint appended). In this paper (Table 2, p.93) it was reported that there was a relationship between aspects of relatives' personality as assessed by an Eysenck Personality Questionnaire (Eysenck & Eysenck, 1975) and their reports of changes in the injured persons. In particular, there was no significant relationship between their Extraversion or Psychoticism scores and their reports of changes in the injured persons. However, the higher their Neuroticism score, the more changes they reported in the injured person - and this especially applied to reported emotional changes in the injured person.

The question arose as to whether the reported emotional changes in the patients were merely a reflection of relatives' personality. It was concluded however that "the influence of personality is not overwhelming" (McKinlay & Brooks, 1984, p.94). When partialling and covarying procedures were carried out to control for the influence of personality, the conclusions of the earlier paper (McKinlay et al, 1981) stood. In particular, it remained the case that relatives reported subjective and emotional changes in the patients more frequently than other kinds of change, and that emotional and behavioural changes were most closely related to stress in relatives.

These data have been further analysed. The scores from each scale on the personality measure, N (Neuroticism), E (Extraversion) and P (Psychoticism) were correlated with each of the 10 summary variables at each of the 3 follow-up times. This gave 3 x 10 x 3 = 90 correlations. Seven of these reached the 5% significance level, two of which also reached the 1% level. The correlations showed no pattern except in the case of reported emotional changes in the patient which correlated at each follow up with the relative N score: at 3 months the correlation was .36 ($p<.05$), at 6 months .38 ($p<.01$), and at 12 months .31 ($p<.05$). As in the previous analyses (McKinlay & Brooks, 1984), partialling and covarying procedures indicated that the relationship between reported emotional changes in the patient and subjective burden stood independently of neuroticism, at least at the two later follow-ups. In particular, when the data were analysed using an analysis of covariance, the relationship remained highly significant at 6 months ($p<.01$) and 12 months ($p<.001$) after allowing for the influence of neuroticism. However, the relationship at 3 months became non-significant ($p>.05$). As before the influence of personality on the accounts given is present but not overwhelming.

CHAPTER 8

FURTHER STUDY - EUROPEAN BRAIN INJURY SOCIETY (EBIS) PROJECT

The present writer was part of a group which carried out a Europe-wide study on patients who had sustained severe brain injury. The study was conducted by the European Brain Injury Society (EBIS) with the support of the Directorate General for Science, Research and Development - DGXII - of the Commission of the European Union. The data presented here were gathered in the process of developing a survey instrument. This has now been published, in 1994, on behalf of the European Brain Injury Society (EBIS) by the Institut de Recherche International Servier (IRIS).

The writer was one of the authors of the assessment schedule, which was composed during a series of meetings between 1988 and 1991. The contributors came from a wide range of professional backgrounds (physicians, psychologists, occupational therapists, social workers, representatives of family organizations, etc) mainly from the countries of the European Union.

The intention was to produce a patient evaluation protocol (or "chart") which can be completed, for the most part, by any experienced member of the care or rehabilitation team, and which will provide a comprehensive overview of problems and, importantly, provide prompts for further action.

After the meetings to develop the measure, field trials were conducted. These were to assess how "user-friendly" the measure was, to look for inconsistencies (e.g. translation problems or unreliable items), and to gather data. These data would be of inherent interest and would also allow for assessment of validity. This was done by having a number of contributors (including the writer) analyze a section of data each, and compare and contrast the findings across measures (asking "are there inconsistencies?") and with the existing literature.

These field trials took the form of a multi-centre study in which collaborators identified patients who had been referred to their units after head injury, and most patients included had sustained head injury of very considerable severity. This was not an epidemiological study of a representative sample (although such a study was carried in Bordeaux as a part of the overall project - Masson, in press).

However, despite the fact that patients were included simply because they were available in the survey period, and also bearing in mind the variety of methods of triage involved in patients reaching the services which form part of the study, nevertheless the sample is of interest. It is a large (n=562) sample and it is well-described in terms of demographic and severity indices.

Much of the literature on brain injury is based upon samples gathered from particular units at a particular time, and not necessarily representative of a defined population in a defined area. Provided samples are well-described, it is reasonable to draw conclusions provided, of course, that the nature of the sample is borne in mind.

The present data are from 425 male and 134 female subjects (3 cases were not clearly coded) seen at a variety of follow-up times, spread between up to three months and over two years. Age is described in Table E1.

AGE	Mean = 29.3	sd = 12.4
	Range 6-84	
	Percentage in age bands	
	6-15	2.5
	16-20	21.7
	21-25	27.3
	26-30	13.3
	31-35	11.1
	36-40	6.5
	41-45	4.7
	46-50	4.8
	51-55	3.8
	56-60	2.1
	60-84	2.2
	N=557	TOTAL=100.0

TABLE E1
EBIS STUDY - BASIC DEMOGRAPHIC DATA - AGE

Other demographic features of the sample are described in Tables E2 (Marital Status), E3 (country of residence), and E4 (country of residence).

	number of cases	percentage of sample
Single	353	62.9
Married/Cohabiting	159	28.3
Widowed	11	2.0
Separated/Divorced	35	6.2
TOTAL	558	

TABLE E2
EBIS STUDY - BASIC DEMOGRAPHIC DATA - MARITAL STATUS

	number of cases	percentage of sample
Special school	15	2.7
Normal school	224	75.0
Higher education	117	21.0
Other	7	1.3
TOTAL	556	

TABLE E3
EBIS STUDY - BASIC DEMOGRAPHIC DATA - EDUCATIONAL LEVEL

	number of cases	percentage of sample
France	313	55.7
UK	120	21.4
Italy	53	9.4
Spain	20	3.6
Denmark	18	3.2
Belgium	11	2.0
Germany	10	1.8
Canada (Montreal)	10	1.8
Netherlands	4	0.7
Israel	3	0.5
TOTAL	562	

TABLE E4
EBIS STUDY - BASIC DEMOGRAPHIC DATA - COUNTRY

These demographic data show a young sample, as in the Glasgow data, with a mean age of 29 and a male:female ration of 3:1. Most had normal education although a small number (15) had required special schooling. The largest part of the sample was carried out in France with the UK providing the next largest data set, which was coordinated by the writer who also collected some of the UK cases.

The nature of the injuries sustained may be gauged from the severity data in Tables E5 and E6 which provide Glasgow Coma Scale (GCS) and Post-Traumatic Amnesia (PTA) data.

Glasgow Coma Scale Total Scores	number of cases	percentage of sample
3-5	189	52.1
6-8	98	26.9
9-12	28	7.7
13-15	48	13.2
TOTAL	363	

For some analyses, the sample was divided into two by Glasgow Coma Scale scores as follows:

More severe (3-5)	189	52.1
Less severe (6-15)	174	47.9

TABLE E5
EBIS STUDY - BASIC CLINICAL DATA - INJURY SEVERITY - GLASGOW COMA SCALE

It is clear from these data that this sample, overall, is a very severely injured one indeed. The biggest group, over half the sample, falls in the GCS range 3-5, consistent with "very severe" injury, the most severe category on the GCS.

As regards the other widely used severity index, PTA duration, these data are provided in Table E6.

Duration of Post-Traumatic Amnesia (PTA)

	number of cases	percentage of sample
< 1 hour	15	3.1
1-24 hours	24	5.0
1-7 days	35	7.3
8-28 days	94	19.7
29-60 days	84	17.6
> 60 days	225	47.2
TOTAL	477	

For some analyses, the sample was divided into two by PTA duration as follows:

The most severe (PTA over 60 days)	225	47.2
Lesser severity (PTA up to 60 days)	252	52.8

TABLE E6
EBIS STUDY - BASIC CLINICAL DATA - INJURY SEVERITY - PTA DURATION

This index also indicates that this sample was overall very severely injured. Nearly half were in the longest PTA category used in the study, that of PTA in excess of 60 days. 64.8% of the sample had more than a month of PTA, putting them into the most severe category generally used, that of "extremely severe" injury (Jennett & Teasdale, 1981).

These cases were each followed up on one occasion only. The range of follow-up times is given in Table E7.

	number of cases	percentage of sample
Up to 3 months	158	28.5
4-6 months	152	27.4
7-12 months	88*	15.9
Over 1 year	156*	28.2
TOTAL	554	

* These 244 "late" cases were used in the more detailed analyses.

TABLE E7
EBIS STUDY - TIME POST INJURY AT ASSESSMENT

Follow-ups ranged from under 3 months to over a year, with some over 2 years post-injury. Comparisons made over time are therefore cross-sectional rather than longitudinal, and allowance has had to be made for the fact that the late cases tended to have been more severely injured than the early cases. For the earliest group, seen up to 3 months post-injury, mean GCS total score is 8.65. For those seen 4-6 months post-injury mean GCS is 6.05, and for those seen 7-12 months post-injury mean GCS is 5.86. The "late" group, seen over 1 year post-injury, have a mean GCS of 5.21. Such a bias is to be expected, as the more severely injured are likely to spend longer in hospital and to have more prolonged contact with the rehabilitation services, and therefore to have been more accessible to the study. Nevertheless, the overall tendency for later cases to be more severely injured is highly significant when assessed by one-way ANOVA (F=20.89, df=3, p<.001). The Bonferroni procedure shows that the earliest group differs from all others (p<.05), but shows no other statistically significant between group differences.

How the injuries were sustained is shown in Table E8. A larger proportion (more than three-quarters) had sustained their injuries in road traffic accidents than in the Glasgow study, possibly reflecting the higher incidence of road traffic accidents in France and the fairly high number of assaults and industrial accidents in Glasgow.

	number of cases	percentage of sample
RTA	439	78.4
Work	33	5.9
Sport/recreation	21	3.8
Fall at home	18	3.2
Assault	25	4.5
Other	24	4.3
TOTAL	560	

TABLE E8
EBIS STUDY - TYPE OF ACCIDENT

It is perhaps also helpful to show the overall outcome in this group before going on to consider certain specific features. Glasgow Outcome Scale data were available and are shown in Table E9. All sentient survivors are included. (One case included in the study who was rated as being in a Vegetative State is not included).

	number of cases	percentage of sample
Good Recovery	141	29.1
Moderate Disability	177	36.5
Severe Disability	167	34.4
TOTAL	485	

TABLE E9
EBIS STUDY - GLASGOW OUTCOME SCALE

The percentages falling into the good recovery (GR), moderate disability (MD), and severe disability (SD) groupings of the Glasgow Outcome Scale are shown and it can be seen that, unlike many previous studies which have had on average less severely injured subjects, in this study the GR group was the smallest with the MD and SD groups each being of approximately equal size.

A variety of analyses were carried out by various members of the team in order to establish acceptable reliability of the scale as a whole, this being done by means of two raters assessing the same patient at the same time. It is perhaps best to quote directly from the introduction to the assessment chart:

> "....the chart's reliability was assessed in terms of inter-rater reliability. Specifically, two examiners both used the chart to examine the same patient (this was done on 15 patients in all), and differences between the two examiners were identified. The items which resulted in these differences were scrutinised and where necessary changed or (more commonly) simply removed".

Although this is not the most demanding method of establishing reliability, it does nevertheless provide the reassurance that ambiguous and difficult-to-code items are not included.

As regards validity, the approach taken (to which reference has already been made) was to seek to replicate known findings in the literature and to ensure that items were internally consistent, i.e. were not producing what appeared to be contradictory or impossible outcomes. Data relating to functional competence was of particular interest to the present author who was responsible for the analysis and presentation of a consideration of validity to the group.

The whole set of analyses will not be rehearsed here but some examples may be useful. The presence or absence of difficulties with various "activities of daily living" was considered. As well as looking for impossible conflicts and considering whether results were reasonable in the light of the literature (while bearing in mind the very severely injured nature of the sample), it was also considered that ADL difficulties would reasonably be expected to be related to capacity for learning in this group. The relationship between various ADL items and learning capacity is shown in Figure 1. It will be seen that in every case the direction is as predicted with all contrasts (by means of t-tests) being highly significant. Moreover, the amount of help needed in caring for the patient as regards both physical and mental help also bore a significant relationship to learning ability (Figure 2). A further example is the comparison of a number of items to Glasgow Outcome scale and Figures 3-5 are example showing the highly significant interactions which were (as would be expected) found. (Weaker effects were found for more complex tasks).

These are examples of the types of analyses carried out. This exercise did lead to the identification of some difficulties in translation which had arisen and any such data are not included in the analyses reported here. An example of a possible difficulty arose over the question of whether individuals required a legal guardian, which was considered in relation to Glasgow Outcome Scale. The Chi-square was highly significant in the expected direction but the presence of six cases who were deemed to require a guardian but who had also made a Good Recovery (Glasgow Outcome Scale) did raise the question of whether there had been an error or inconsistency in the ratings made as on the face of it, for an adult to require a legal guardian would appear to be incompatible with a good recovery. However, this seeming conflict was largely explicable in terms of there being a number of children in the study. Apart from some clear errors of translation which emerged, there were few such conflicts and they were not considered to represent an unacceptable level of error particularly in a multi-centre international study.

As regards the findings of the EBIS study, first the overall symptom pattern was considered. For these analyses and indeed most of the analyses of the EBIS data, only "late" outcome was considered, i.e. those cases seen at over 1 year post-injury. Since the main focus of interest is on psychosocial problems and burden, firstly the frequency of the psychosocial items in the chart is summarized. The accounts of carers and patients are shown alongside each other (as exactly comparable items were used for each).

Out of these 20 items, 18 are reported less often by patients than carers. In the other two items, one was reported by the same percentage and one (mood changes) by 1% more patients. This is consistent with the finding previously reported (McKinlay & Brooks, 1984) that where

PERCENTAGE OF CASES WITH "LATE" PSYCHOSOCIAL PROBLEMS DUE TO INJURY	CARER	PATIENT
Irritability	71	61
Aggression	28	19
Agitation	32	23
Excessive talking	30	24
Embarrassing social behaviour	39	30
Embarrassing sexual behaviour	13	8
Inappropriate eating	27	20
Childish behaviour	54	34
Obsessional behaviour	50	29
Lack of concern with hygiene	24	5
Lack of volition	65	48
Manic behaviour	32	32
Mood changes	35	36
Poor temper control	72	62
Callous/uncaring behaviour	36	29
Social withdrawal	51	43
Depressed mood	57	53
Suspicious behaviour	35	32
Hostile behaviour	39	24
Anxiety	55	50

TABLE E10
FREQUENCY OF PSYCHOSOCIAL PROBLEMS, AT OVER 1 YEAR POST-INJURY, AS REPORTED BY CARERS AND PATIENTS (PERCENTAGE REPORTING)

there is disagreement between patients and relatives, it is usually the case that the patient fails to report or denies a problem reported by the relative.

The total number of problems reported by relatives (out of 20) averages 7.6 while the figure for patients is 6.4. This however is a statistically significant difference ($t=4.53$, $df=155$, $p<.001$). While it has been considered, on clinical ground that relatives' accounts are more realistic (although themselves open to influence - see McKinlay & Brooks, 1984), simple analyses were carried out in relation to this issue. It might reasonably be expected that the most severely injured would have more problems than the least severely injured. Do the accounts of carers and patients reflect this?

The accounts of neither carers nor relatives reflected injury severity, with no consistent trend across group means and the one-way ANOVA non-significant. However,by the time the summary variables had been composed, and compared with GCS data, numbers were modest for some of the subgroups.

Before coming to further analyses of burden, one question of some interest was the question of whether claims for financial compensation played any significant part in the presentation of these patients. A previous study based on the material for the main part of this thesis was published and found few differences between those claiming compensation and those not (McKinlay, Brooks & Bond, 1983). In this earlier study, no significant differences were found between claimants and non-claimants in terms of psychological tests; and moreover there were no significant differences in the pattern of symptoms reported by relatives. There was a slight difference in terms of the patient's own reporting between those claiming and not claiming compensation: in particular those claiming reported slightly more symptoms than those not doing so and this difference was sufficient to reach statistical significance. It was, however, not a particularly large effect and not one which was reflected in the other two sources of data, i.e. psychological tests and relative's reports.

Since the time of that paper, it is probably fair to say that concerns amongst clinicians about the risks of patients who have had severe head injury exaggerating the difficulties have declined. However, it was nevertheless thought of some interest to compare, in this larger study, those claiming compensation versus those who are not doing so. Out of the sample as a whole therefore, those patients who are not claiming compensation were made to form Group 1 (non-claimants): this was made up of 143 cases (30.8% of those where compensation data were available). Those who had a claim for compensation which remained outstanding were made to form Group 2 (claimants): there were 243 such cases (52.4%). The remaining 16.8% had had their claims settled at the time of assessment.

The groups did not differ significantly in terms of severity of injury as assessed by GCS or PTA (see Tables E11 and E12). It can be seen that the Chi-square does not show a significant difference and inspection reveals a broadly similar distribution of cases in the no-claim and claim groups as regards both PTA duration and GCS total scores.

The further Table E13 shows the age/sex distributions which are statistically significantly different (age - t-test - p<.01; sex - chi-square - p<.001). Overall,

PTA	No Claim	Claim
< 1 hour	4	5
1-24 hours	4	15
1-7 days	11	9
8-28 days	26	44
>28 days	72	145

Chi-square: ns (p>.05).

TABLE E11
CLAIM v NO CLAIM GROUPS - COMPARISON OF SEVERITY IN TERMS OF PTA DURATION

GCS	No Claim	Claim
3-5	43	93
6-8	25	43
9-12	11	10
13-15	7	21

Chi-square: ns ($p>.05$).

TABLE E12
CLAIM v NO CLAIM GROUPS - COMPARISON OF SEVERITY IN TERMS OF GCS TOTAL SCORE

NO CLAIM GROUP
Age: Mean=31.8 sd=14.4
Sex: M=124 cases F=18 cases

CLAIM GROUP
Age: Mean=27.5 sd=11.4
Sex: M=173 F=69

TABLE E13
AGE/SEX IN CLAIM/NO CLAIM GROUPS

therefore, the claim and no-claim groups do not differ significantly in terms of severity data. There are differences in age and sex which are highly statistically significant, but are unlikely to be of major clinical significance although should the groups differ clinically the contribution of these variables could be taken into account.

A broad comparison of outcome was made by comparing claim and no-claim groups on Glasgow Outcome Scale. If compensation was a significant factor in affecting the broad overall clinical presentation of a significant number of patients one might expect that this would be reflected in differences in GOS across groups. It can see from Table E14 that there is no significant difference between claim and no-claim groups on Chi-square.

GOS	No Claim	Claim
Good Recovery	89	44
Moderate Disability	167	68
Severe Disability	43	32

Chi-square: ns (p>.05).

TABLE E14
CLAIM v NO CLAIM GROUPS - COMPARISON OF GLASGOW OUTCOME SCALE

The mean total number of problems reported by claimants or found in claimants was considered next. Firstly, the number of physical problems assessed in the patient by the examiner was summed and compared across groups. This difference was not significant (t=1.05, df=191.87, p>.05).

Then the degree of independence shown was considered firstly in relation to "basic" activities of daily living (ADLs) such as walking, standing, toileting, etc. There was no significant difference (t=.44, df=222.68, p>.05) between groups here or on advanced ADLs (such as menu planning, handling money) (t=-.24, df=186.16, p>.05).

The degree of disruption to family health and activities was also considered: in claimants 2.4 such problems were present (out of 10) on average while non-claimants had 2.8

such problems. Again, however, the groups did not differ (t=-1.31, df=217.55, p>.05). The same was true of cognitive problems (t=.05, df=235.24, p>.05).

In the present context, psychosocial problems are of particular interest. The list of psychosocial problems given in Table E10 was summed. Informants (carers) reported an average of 6.4 of these in claimants and 6.4 in non-claimants (t=.03, df=282.70, p>.05). When the patients' replies to the same questions are considered, the claimants on average report 5.7 items compared to the non-claimants' 6.0 items. Again, this is not significantly different (t=-.76 ,df=287.86 ,p>.05).

Therefore, there were no claimant v. non-claimant differences identified. These results therefore are broadly in line with those previously reported on the main group in this study (McKinlay et al, 1983), the only difference being that the slight tendency of claimants themselves to report more difficulties was not replicated here.

The question arises of whether in this group, like others previously reported in the literature, and indeed the main study group, there is continuing or even worsening family distress and "burden" on carers. Two forms of "burden" were assessed in addition to the patient changes outlined. The extent of carer's subjective burden was again rated on a 7 point analogue scale.

	mean subjective burden
Up to 3 months	4.1
4-6 months	4.6
7-12 months	4.9
Over 1 year	4.9

TABLE E15
EBIS STUDY - TIME POST INJURY AT ASSESSMENT

The overall significance of the change over time was assessed by one-way ANOVA: F=6.29, df 3,446, p<.001. Bonferroni tests showed that the earliest group differed significantly from all the other groups (p<.05). Bearing in mind that earlier cases were to some degree less severely injured, the data were reanalysed with severity (GCS) as covariate. The significance of the change now disappears: and after the effects of severity are controlled in this way, there is no significant change over time.

Next, family burden was assessed. Eight variables relating to disruption to family life and adverse effects on the health of family members were extracted from the data set. Table E16 shows the frequency of each at each follow-up time.

TABLE E16/

Note <3m=1 4-6m=2 6-12m=3 >1yr=4

	1	**2**	**3**	**4**
Family member sought help	28	27	40	43
Family suffering financially	32	29	42	39
Family member given up work	23	24	31	37
Change in family roles	16	20	32	36
Change in social relationships	25	29	57	67
Behavioural problems with children	17	32	43	37
Respite needed	16	11	30	41
Family unable to cope	6	6	11	18

TABLE E16
FREQUENCY OF "FAMILY BURDEN" ITEMS AT EACH FOLLOW UP PERIOD

The significance of these changes was then assessed. Firstly, a series of one-way ANOVAs was carried out and the results are summarized in Table E17. Because of the confounding effect of injury severity which has been mentioned earlier, GCS total score was then used as covariate. This led to the disappearance of some of the initially significant results, which had essentially been an artifact of severity.

Changes in family roles, restriction in social relationships, and need for respite were the variables which showed a real increase at later follow-ups, allowing for severity effects.

Note <3m=1 4-6m=2 6-12m=3 >1yr=4

The initial p value is the 2-tailed significance of the one-way ANOVA, and the group comparisons show individual groups which differed from each other on Bonferroni comparisons (p<.05). The ANCOVA used GCS as covariate.

Family member sought help	p<.05	1,2 v 4	ANCOVA ns
Family suffering financially	ns		ANCOVA ns
Family member given up work	p<.05	1,2 v 4	ANCOVA ns
Change in family roles	p<.001	1 v 3,4 2 v 4	ANCOVA p<.01
Change in social relationships	p<.001	1,2 v 3,4	ANCOVA p<.001
Behavioural problems with children	p<.01	1 v 2,3,4	ANCOVA ns
Respite needed	p<.001	1,2 v 3,4	ANCOVA p<.01
Family unable to cope	p<.01	1,2 v 4	ANCOVA ns

TABLE E17
SIGNIFICANCE OF CHANGES IN "FAMILY BURDEN" OVER TIME

Further analyses have been carried out, and for this purpose a measure of the disruption of family life was made by summing the number of these changes present in each case. (This gave a range from 0-8). The distribution of this at all follow-up times is shown in Table E18. However, in line with the main part of the present discussion, attention was focused on those seen at 12 months post-injury or later. This gives a reasonably-

"FAMILY" BURDEN

Total number of items reported in each case

	number of cases	percentage of sample
0	183	32.6
1	91	16.2
2	96	17.1
3	65	11.6
4	50	8.9
5	45	8.0
6	22	3.9
7	8	1.4
8	2	.4

"Low" burden (0-3) n=370
"High" burden (4-8) n=192

TABLE E18
FAMILY BURDEN - ALL FOLLOW UP TIMES

"FAMILY" BURDEN

Total number of items reported in each case

	number of cases	percentage of sample
0	34	13.9
1	33	13.5
2	49	20.1
3	41	16.8
4	28	11.5
5	34	13.9
6	16	6.6
7	7	2.9
8	2	.8

"Low" burden (0-3) n=116
"High" burden (4-8) n=128

TABLE E19
FAMILY BURDEN - 12 MONTHS OR MORE POST-INJURY

sized late group who do not show any significant difference within the group in terms of injury severity x time post-injury. The distribution of burden in this group is shown in Table E19 on which is marked a cut-off which gives the most equal split possible for these data. Those falling below the cut-off were designated "low" burden and those above it "high" burden.

As one might expect, burden so measured shows a relationship, albeit not an especially strong one, to injury severity. Family burden shows a relationship to severity, especially as measured by post-traumatic amnesia duration, while subjective burden does not.

	LOW "family" burden	HIGH "family" burden
GCS 3-5	15	42
GCS 6-15	13	11

Chi-square: p<.05

TABLE E20
CROSSTABULATION OF "LATE" CASES: FAMILY BURDEN BY SEVERITY OF INJURY (GCS)

	LOW "subj." burden	HIGH "subj." burden
GCS 3-5	16	34
GCS 6-15	7	15

Chi-square: ns

TABLE E21
CROSSTABULATION OF "LATE" CASES: SUBJECTIVE BURDEN BY SEVERITY OF INJURY (GCS)

	LOW "family" burden	HIGH "family" burden
PTA <2m	26	12
PTA >2m	28	62

Chi-square: p<.001

TABLE E22
CROSSTABULATION OF "LATE" CASES: FAMILY BURDEN BY SEVERITY OF INJURY (PTA)

	LOW "subj." burden	HIGH "subj." burden
PTA <2m	9	23
PTA >2m	24	52

Chi-square: ns

TABLE E23
CROSSTABULATION OF "LATE" CASES: SUBJECTIVE BURDEN BY SEVERITY OF INJURY (PTA)

Given that severity does not account well for burden, a series of analyses was carried out to try to relate both family and subjective burden to particular psychosocial sequelae.

Burden was next compared with a number of summary variables, with the results summarized in Table E24. The detailed results are in Appendix 1, Tables E25 to E64. For these analyses, chi-square was used. The distributions of the variables, with the symptom variables being "yes/no" and the subjective burden distribution being very skewed to the top end, did not suggest that any other approach would be appropriate. Comment on some individual comparisons is made in the discussion and the overall results are summarized in Table E24.

SUMMARY of Chi-square analyses

	OB	SB
Irritability	*	+
Aggression		
Agitation	+	
Excessive talking	+	
Embarrassing social behaviour	+	
Embarrassing sexual behaviour	*	
Inappropriate eating	+	+
Childish behaviour	+	*
Obsessional behaviour		*
Lack of concern with hygiene	**	
Lack of volition		
Manic behaviour	*	
Mood changes		+
Poor temper control	*	*
Callous/uncaring behaviour		+
Social withdrawal	*	*
Depressed mood		
Suspicious behaviour		+
Hostile behaviour	+	*
Anxiety	*	+

\+ $p<.05$ * $p<.01$

To these tables must be added that there was not a significant relationship between family burden and the extent of physical or cognitive difficulty, nor was there a relationship with basic activities of daily living (ADLs) but problems with advanced ADLs were related to family burden (Chi-square: $p<.001$). Lastly, the relationship between Subjective and Family Burden is summarized in Table E65 (Appendix 1) and receives comment in the final chapter.

CHAPTER 9

DISCUSSION

It is well established that serious physical disability is comparatively rare even in those with severe head injury, but that what have come to be called "psychosocial" problems are much more common (e.g. McKinlay et al, 1981). The present analyses, considering this in a slightly different way, again show that physical and sensory problems are not as common as psychosocial ones. Moreover, neither was found to correlate (Ch.7) with carer's subjective burden.

In both Glasgow and EBIS studies however, continuing problems in long-term follow-ups of those with TBI are apparent. In the Glasgow study few items show change over time to a statistically significant extent although it is in psychosocial area rather than physical or sensory areas that the majority of items were likely to be showing an increase. In the more-severely injured EBIS group, the "family burden" approach was more fully explored. This showed much apparent increase over time but mostly these changes proved an artifact produced by severity differences between time groups. However, adverse changes in social relationships and changes in family roles especially, and also need for respite, emerged as aspects of family burden which show a real increase over time.

All of this is entirely consistent with findings from studies of long-term follow-up at 7 years (Oddy et al, 1985) and at 10-15 years (Thomsen, 1984): these have shown considerable similarity with poor memory and concentration, poor control of temper and tiredness amongst the most common problems reported. That these fail to resolve and some reportedly increase has prompted discussion and led McKinlay & Brooks (1984) to suggest that this increased reporting may reflect either a secondary psychological disorder in reaction to the limitations imposed by TBI or a decreased tolerance by relatives as problems persist.

Studies have continued to appear which reinforce and expand upon these earlier findings. For example, Dikmen et al (1993) reported on subjects with severe head injury which had a significant long-term impact on psychosocial functioning. Many patients were unable to return to work, support themselves financially, to live independently, or to participate in previously enjoyed leisure activities in the two years following injury. Initially the patients' self-reports had focused on physical limitations, but as these problems began to resolve there was a heightened awareness of psychosocial limitations. Whereas fatigue, headaches, dizziness, and insomnia were amongst symptoms showing decline from one month to two years, complaints of memory difficulties and irritability showed the clearest increases over the same period. Linn et al (1994) also suggest that there is an increase in either awareness or incidence of problems over time. In their sample population of 60 TBI individuals (averaging 6 years post-injury) and their spouses, they found that both individuals with TBI and their spouses showed elements of depression and anxiety: 70% or more in each group had at least mild depression, while 50% or more showed at least mildly elevated anxiety.

As regards distress, this was measured in the Glasgow study by carer's "subjective burden" although some "family burden" items were also included. The EBIS study includes a fuller set of "family burden" items. Neither study provided evidence of a statistically significant increase in subjective burden over time. In the Glasgow group there was virtually no change from 3 to 12 months. In the EBIS group, what appeared to represent an increase was largely accounted for by severity differences between subgroups, and no significant difference over time remained.

What is related to burden has already received some attention. It has previously been noted (McKinlay et al, 1981) that age and severity (PTA duration) are poor predictors of burden but that it seems to be mediated by particular changes in the patient. The issue of causality and influence in accounts has been considered previously too by McKinlay & Brooks (1984) and more recently by Kreutzer (1994). In the Glasgow data, which have been subdivided to try to give a more precise set of relationships, without grouping together rather disparate items as previously, it is emotional and behavioural changes in the patient which are associated at every follow-up time (at the 1% significance level at least) with subjective burden. Self-care problems show an association up to 6 months then drop out, which is probably not surprising given some probable degree of resolution. However, from 6 months onwards, emotional and behavioural changes in the patient are joined by subjective changes, speech-language and cognitive problems, and violent or "obsessional", routine-bound behaviour as predictors or burden.

In the EBIS study, both forms of burden were studied mainly in late cases (i.e. over 1 year post injury). The relationship between both forms of burden (carer's "subjective burden", and "family burden" which is the degree of disruption to family health and activities) and severity was generally weak. The exception was that PTA duration (one of the severity indices used) was strongly related to family burden. The particular changes in the patient which related to these burdens were studied in some detail. The very skewed distribution for much of these data was noted, and also that subjective burden especially was very often "severe". Simple analysis by chi-square tables was therefore chosen and this has the benefit of showing that the relationships between particular problems is seldom linear. Very often, see (as one of many possible examples) Table E34: there is very seldom a low burden where there is a lack of concern with hygiene, but the obverse is not true. In other words many of these items, if present, seem certain also to be found with high burden, but if they are absent burden may be high or low, presumably depending on other variables. Table E24 (p.154) summarizes the changes in the patients which relate to both subjective and family burden. Subjective burden is especially related to childish and obsessional behaviour, poor temper control, social withdrawal, and hostile behaviour. Family burden on the other hand is especially related to irritability, embarrassing sexual behaviour, lack of concern with hygiene, manic behaviour, poor temper control, social withdrawal, and anxiety. It is hard to characterise just what kinds of variable are related to each with confidence, but it seems reasonable to suggest that the more overt emotional and behavioural problems cause most family burden, while at least some of those which are especially related to subjective burden would be less evident to outsiders but would have a corrosive effect on close relationships.

It is also relevant here to consider the relationship between the two forms of burden (Table E65, Appendix 1). There is a highly significant association between them ($p<.001$) but there are also differences. There are many more cases where Subjective Burden is high while Family Burden is low than vice versa and this may reflect the particular burden on carers imposed by those changes in intimate, previously confiding relationships, changes which are not necessarily overtly disruptive.

It was also noted, perhaps not surprisingly, that problems with "advanced" activities of daily living (i.e. which generally involve some initiative and planning) were especially associated with family burden.

It has of course been widely discussed in the literature that it is not just the individual with TBI who suffers from these long-term problems, but also that the family have to bear some of the impact of the brain injury and that they are frequently under considerable strain and can experience extreme stress. Lezak (1988) carried out a review of emotional and behavioural alterations after brain injury and the effects on family members. She explains that shame and guilt along with frustration and anger may be felt from having a "different" family.

The picture which emerges is that physical problems, although they are present and may be severe in some TBI cases, are not the main issue for long-term management. Rather, the difficulties reside primarily in the emotional and behavioural changes which follow brain injury and which are a particular source of distress to relatives. These together with cognitive deficits present difficulties in terms of return to work (e.g. Brooks et al 1987, which is based in part of the Glasgow data reported here).

It should also be noted that a previous study, based on the present Glasgow data, was on compensation (McKinlay et al, 1983). The opportunity was taken, in the context of the EBIS data, to look at this matter again, and no differences in clinical presentation were found between those with no claim and those with outstanding claims.

A theme which has increasingly emerged in the literature is that of social isolation. Individuals with TBI often no longer perform adequately in social situations and may begin to avoid them. Ponsford et al (24) reported that 50% of individuals who had suffered TBI reported social isolation as a behavioural change at 2 years post-injury. Thomsen (20) investigated the late outcome of traumatic brain injury, examining individuals at between 10 and 15 years post-injury (her 2nd follow-up). She found that:

> "At the second follow-up two-thirds had no contact outside the close family, and social isolation remained the patients' severest burden ...... Several preferred to make friends with old people, since they were kind and patient." (20, p.265)

Finset, et al (25) report on a similar finding in a sample of individuals with TBI at 2 years after admission to a rehabilitation hospital. 57% of the sample reported that their social networks had "markedly declined" since their injury. Where social support remained it was mainly received from family members rather than from friends or neighbours. Finset et al propose that the degree of support received from family members is reflective of the family's perception of the severity of the injury sustained. This is based on the finding that those individuals with a shorter length of coma perceived their social networks and support from family as being poorer than those with a more severe injury (a longer period of coma). Of course, those individuals who have sustained a more severe injury may be exaggerating the support they receive and the networks that remain as a result of a lack of insight or as a result of a more severe memory impairment.

Thomsen did not just comment on the psychosocial experiences of the individuals with TBI but also commented on the corresponding effects on the families:

> "While lack of social contact at the former [first follow-up, average 2.5 years post-injury] was the greatest subjective burden to the patients, changes in personality and emotion presented the severest problem to the families. The spouses of the seven patients who had a divorce declared that their wives or husbands had become complete strangers. Loss of emotional control, with rapid changes between apathy and aggression, irritability, and childishness were the main complaints. The relationship between the

> patients and their children developed badly in all cases and the spouses considered themselves the only grown-ups in the families." (20, p.264)

Florian et al (1989) reviewed the dynamics and functioning of families with a severely head injured member. They noted it has been assumed that these families are faced with adjustment problems different to those arising from other forms of disability. They draw comparison between brain damage (BD) and spinal cord injury (SCI). They chose this because the majority of both groups are young males; the disabilities arise from irreversible neuro-trauma requiring lengthy hospitalisation; and they generally require a change in the roles of spouse or other family members. They do however note that there is a fundamental difference between the two disabilities. They observed that both require a drastic change in the life of the injured person. They note that changes in personality and behaviour are common in BD and that these emotional and behavioural changes are as a result of "complex interactions among the neurological deficits, existing social demands, behaviour styles from the past" and the responses of the person with BD to all of these. They note a tendency on the part of such individuals to use "inflexible and often primitive defence mechanisms".
The impact on the life of family members is also described by Florian et al. They report a study by Vargo who

evaluated the influence of disability on the wives of SCI patients. A process of adjustment is described, but as Florian notes, in the case of families with a brain damaged member, the picture is different. High levels of stress and strain continue to be reported, which it is suggested "appear to be related more to the daily coping with the disability, rather than to the severity of the initial injury". The findings in the present study showing the importance of advanced ADL in relation to burden is relevant.

The use of a comparison group, as in the Florian et al study, was in fact also begun in the present research, and recruitment of a spinal-cord injured (SCI) group began alongside collection of the data set described in Chapter 7. However, the group proved to be very different from the head-injured group in terms of demographic characteristics and premorbid adjustment, with several of the SCI group being injured in suicide attempts. Comparison was therefore going to be of little value and this exercise was discontinued. As explained in the Method section, the present study was in any event framed in terms of assessing <u>change</u>, so that a comparison group was not essential.

Leathem et al (1995) note that the disabilities resulting from TBI can be divided into physical, cognitive and behavioural/emotional and comment on the greater significance of cognitive, behavioural [illegible] emotional difficulties. This study was concerned with social support and particularly was to examine the nature and extent of role change, the utilisation of social support and the stress experienced by relatives. Eighteen patients were studied, and it seems that partners showed more change than parents in relation to household and financial role changes. The extent of role change showed a small relationship to the extent of stress and there was a negative relationship between stress and measures of social support. The authors note that further investigation of stressors after head injury continues to be essential, they also suggest that guilt about the idea of separation or divorce may contribute to down-playing of relationship difficulties.

A review by Morton and Wehman, Brain Injury 1995 is also relevant. The psychosocial problems of decreased social contact, depression and loneliness create a major challenge for community re-entry. Psychosocial problems remain persistent and are the major challenge facing rehabilitation.

Finally, I would refer again to the two important studies by Kreutzer and his colleagues (Kreutzer et al, 1994a, 1994b) which were essentially a replication and extension of previous work in Europe including that of the present writer. They investigated the prevalence of psychological distress and family dysfunction amongst primary carers of

62 subjects. They note that the lengthy process of recovery and the sudden alteration of the brain injured person's abilities or personality are especially taxing for relatives and carers. The family's responses to brain injury are of great concern to rehabilitation professionals in order to facilitate community re-entry. They note that extensive previous research had been carried out in Europe and note that, at least at the time of the conducting of previous research studies, including by the present author, co-ordinated services for the brain injured were virtually non-existent in the United Kingdom. They note the high "subjective burden" which has been found previously in studies in Glasgow.

Their carers showed high scores in depression, anxiety and other scales, reflecting increased stress and they also found scores suggestive of unhealthy family functioning. Discussing these findings they note that TBI patients show emotional and behavioural symptoms and face the need for long-term rehabilitation. In conclusion, I would agree with these authors that one should caution clinicians against dismissing the depression and other emotional changes following TBI as a passing reaction. Many family members have substantial ongoing problems which warrant the close attention of rehabilitation practitioners with participation and support groups a worthwhile element to try to lessen the feelings of isolation. Family members are a key part of the rehabilitation effort, sometimes explicitly included (e.g. McKinlay & Hickox, 1989), and understanding their dynamics is crucial for optimal readjustment and community re-entry.

APPENDIX 1 - TABLES

AGE (at time of injury):

Range 16-60
Mean 35.3
Standard deviation 14.2

Age Distribution

	Number of cases	Percentage of sample
16-20	12	22.2
21-25	8	14.8
26-30	3	5.6
31-35	4	7.4
36-40	5	9.3
41-45	4	7.4
46-50	8	14.8
51-55	8	14.8
56-60	2	3.7
	54	

TABLE 1
AGE OF SAMPLE

	Number of cases	Percentage of sample
Road Traffic Accident	26	48.1
Assault	11	20.4
Accident at work or home	5	9.3
Falls or "other" causes	12	22.2
Total	54	

TABLE 2
CIRCUMSTANCES OF INJURY AND NATURE OF INJURY.

	Number of cases	Percentage of sample
No	27	50.0
Yes	27	50.0
Total	54	

TABLE 3
NATURE OF INJURY - WAS INTRACRANIAL HAEMATOMA IDENTIFIED?

	Number of cases	Percentage of sample
No	23	42.6
Yes	31	57.4
Total	54	

TABLE 4
NATURE OF INJURY - WAS SKULL FRACTURE IDENTIFIED?

	Number of cases	Percentage of sample
No	27	50.0
Yes	27	50.0
Total	54	

TABLE 5
NATURE OF INJURY - WAS NEUROSURGICAL OPERATION CARRIED OUT?

PATIENT:

3 months post injury
Assessment of PTA, RA. Previous medical history.
Current Symptoms, employment status.
IQ, memory, language assessment.

6 months post injury
Current symptoms, employment status.
IQ, memory, language assessment.

12 months post injury
Current symptoms, employment status.
IQ, memory, language assessment.

RELATIVE:

0-2 weeks post injury
Premorbid information on patient.
Rating of patient's premorbid personality.
Relative's personality

3 months post injury
Premorbid information on patient (if not already collected) and further background information.
Changes in patient, effect on family (survey period 0-3 months).
Ratings of patient's premorbid and current personality.
Relative's personality.

6 months post injury
Changes in patient, effects on family (survey period 3-6 months).
Ratings of patient's premorbid and current personality.
Relative's personality.

12 months post injury
Changes in patient, effects on family (survey period 6-12 months).
Ratings of patient's premorbid and current personality.
Relative's personality.

TABLE 6
SUMMARY OF MEASURES USED AT EACH FOLLOW-UP

TABLE 7 (over 2 pages)
SUMMARY OF FREQUENCIES OF MAIN VARIABLES ON RELATIVE QUESTIONNAIRE (PERCENTAGE REPORTING)

	3	6	12
Physical independence (able to get about?)			
Yes, independently	87.0	90.7	90.7
Yes, with stick/crutch	9.3	5.6	5.6
Confined to wheelchair	1.9	3.7	3.7
Confined to bed	1.9	0	0
Loss/restricted mobility			
Arm(s)	24.1	18.5	14.8
Leg(s)	20.4	14.8	9.3
Weakness			
Arm(s)	38.9	31.5	33.3
Leg(s)	37.0	35.2	27.8
Sight problem	53.8	46.2	42.6
Hearing problem	14.8	11.1	16.7
Loss of sense of taste	12.2	7.5	7.7
Loss of sense of smell	6.3	9.4	11.3
Poor sense of balance	48.0	38.9	40.7
Dizzy spells	25.0	25.9	35.2
Fits (seizures)	5.6	7.4	14.8
Headaches	54.9	45.3	53.7
Intolerance of noise	46.8	40.7	45.3
Tiredness	84.0	69.8	70.4
Slowness (physical)	86.0	68.5	66.7
Often feels unwell	18.0	18.9	13.0
Tense/anxious	56.0	64.8	57.4
Restless/wandering	37.7	44.4	44.4
Poor sleep	21.2	20.8	28.3
Nightmares	2.2	5.8	3.8
Demands attention	34.0	35.2	37.0
Impatience	59.6	63.0	70.4
Irritability	64.2	68.5	70.4
Easily angered	49.1	57.4	66.7
Threats or gestures of violence	17.3	14.8	17.0
Physical violence	7.7	7.5	11.3
Excessive smoking	29.8	33.3	24.5
Easily affected by alcohol	26.8	32.6	46.0
Excessive drinking	6.0	14.0	14.8
After drinking:			
argumentative	17.1	14.6	24.1
threatened violence	7.5	7.3	9.3
physical violence	7.3	4.9	7.4
Trouble with the law	0	1.9	5.6
Upset by changes to routine	20.0	15.7	22.6
Needs tidiness	17.0	20.8	13.2

Suspicious/mistrustful	22.9	22.6	37.0
Bossiness	20.8	11.3	13.0
Nosey/interfering	6.3	13.2	14.8
Odd behaviour/ideas	20.8	20.8	9.3
Problems with			
Speech articulation	33.3	25.9	29.6
Expressive language	46.3	42.6	42.6
Holding a conversation	18.9	25.9	9.3
Understanding speech	9.4	5.6	7.4
Following conversation	14.8	13.0	9.3
Poor memory	72.2	58.5	68.5
Poor concentration	40.4	37.7	39.6
Excessive talking	31.9	24.5	25.9
Laughing for no reason	8.2	11.3	3.7
Laughing for too long	8.2	5.7	9.3
Difficulty behaving in company	11.5	18.9	11.1
Quiet/withdrawn in company	11.8	18.9	27.8
Avoids company	9.4	13.2	18.9
Changes in sex life	50.0	48.3	46.7
Attitude to sex changed	40.9	37.5	38.5
Sexual capabilities changed	23.5	33.3	27.3
Difficulty in washing/ dressing/toileting	17.0	16.7	9.3
Dresses wrong way (e.g. back to front)	0	5.8	3.7
Less concern with cleanliness etc	17.0	18.9	16.7
Enuresis	5.7	3.8	7.4
Clumsy (knocks things over)	21.3	18.9	13.2
Bumps into things	27.7	11.8	24.5
Always accompanied indoors	25.0	15.1	11.3
Unable to be in charge of household	22.4	22.0	22.2
Always accompanied outdoors	29.4	17.0	17.0
Loss of interest	28.3	29.6	24.1
Childish behaviour	34.0	33.3	44.4
Mood changes	32.1	37.0	61.1
Depressed	56.6	50.9	56.6
Worries about future	42.3	37.0	32.1
Refusal to admit difficulties	23.5	24.5	33.3
Personality change	48.1	57.4	59.3

	LOW Objective Burden	HIGH Objective Burden
Irritability NO	45	28
YES	57	90

Significance of Chi-square p<.01

TABLE E25

	LOW Objective Burden	HIGH Objective Burden
Aggression NO	81	86
YES	21	33

Significance of Chi-square ns

TABLE E26

	LOW Objective Burden	HIGH Objective Burden
Agitation NO	79	73
YES	24	45

Significance of Chi-square p<.05

TABLE E27

	LOW Objective Burden	HIGH Objective Burden
Excessive talk NO	80	74
YES	21	37

Significance of Chi-square p<.05

TABLE E28

	LOW Objective Burden	HIGH Objective Burden
Embarrassing social behaviour NO	71	62
YES	31	54

Significance of Chi-square p<.05

TABLE E29

	LOW Objective Burden	HIGH Objective Burden
Embarrassing sexual behaviour NO	95	90
YES	7	26

Significance of Chi-square p<.01

TABLE E30

	LOW Objective Burden	HIGH Objective Burden
Inappropriate eating NO	89	84
YES	14	32

Significance of Chi-square p<.05

TABLE E31

	LOW Objective Burden	HIGH Objective Burden
Childish behaviour NO	57	48
YES	44	71

Significance of Chi-square p<.05

TABLE E32

	LOW Objective Burden	HIGH Objective Burden
Obsessional behaviour NO	66	66
YES	36	51

Significance of Chi-square ns

TABLE E33

	LOW Objective Burden	HIGH Objective Burden
Lack of concern with hygiene NO	91	81
YES	9	30

Significance of Chi-square p<.001

TABLE E34

	LOW Objective Burden	HIGH Objective Burden
Lack of volition NO	40	33
YES	62	82

Significance of Chi-square ns

TABLE E35

	LOW Objective Burden	HIGH Objective Burden
Manic behaviour NO	80	71
YES	22	46

Significance of Chi-square p<.01

TABLE E36

	LOW Objective Burden	HIGH Objective Burden
Mood changes NO	64	71
YES	38	48

Significance of Chi-square ns

TABLE E37

	LOW Objective Burden	HIGH Objective Burden
Poor temper control NO	44	28
YES	58	90

Significance of Chi-square p<.01

TABLE E38

	LOW Objective Burden	HIGH Objective Burden
Callous/uncaring behaviour NO	69	70
YES	32	48

Significance of Chi-square ns

TABLE E39

	LOW Objective Burden	HIGH Objective Burden
Social withdrawal NO	57	45
YES	45	72

Significance of Chi-square p<.01

TABLE E40

	LOW Objective Burden	HIGH Objective Burden
Depressed mood NO	45	44
YES	57	75

Significance of Chi-square ns

TABLE E41

	LOW Objective Burden	HIGH Objective Burden
Suspicious behaviour NO	73	71
YES	29	46

Significance of Chi-square ns

TABLE E42

	LOW Objective Burden	HIGH Objective Burden
Hostile behaviour NO	76	69
YES	25	51

Significance of Chi-square p<.05

TABLE E43

	LOW Objective Burden	HIGH Objective Burden
Anxiety NO	50	37
YES	52	81

Significance of Chi-square p<.01

TABLE E44

	LOW Subjective Burden	HIGH Subjective Burden
Irritability NO	28	36
YES	41	98

Significance of Chi-square p<.05

TABLE E45

	LOW Subjective Burden	HIGH Subjective Burden
Aggression NO	56	97
YES	13	38

Significance of Chi-square ns

TABLE E46

	LOW Subjective Burden	HIGH Subjective Burden
Agitation NO	49	89
YES	19	47

Significance of Chi-square ns

TABLE E47

	LOW Subjective Burden	HIGH Subjective Burden
Excessive talking NO	53	87
YES	15	41

Significance of Chi-square ns

TABLE E48

	LOW Subjective Burden	HIGH Subjective Burden
Embarrassing social behaviour NO	47	75
YES	21	58

Significance of Chi-square ns

TABLE E49

	LOW Subjective Burden	HIGH Subjective Burden
Embarrassing sexual behaviour NO	59	110
YES	9	23

Significance of Chi-square ns

TABLE E50

	LOW Subjective Burden	HIGH Subjective Burden
Inappropriate eating NO	60	98
YES	9	35

Significance of Chi-square p<.05

TABLE E51

	LOW Subjective Burden	HIGH Subjective Burden
Childish behaviour NO	41	54
YES	27	81

Significance of Chi-square p<.01

TABLE E52

	LOW Subjective Burden	HIGH Subjective Burden
Obsessional behaviour NO	52	73
YES	17	60

Significance of Chi-square p<.01

TABLE E53

	LOW Subjective Burden	HIGH Subjective Burden
Lack of concern with hygiene NO	57	101
YES	11	26

Significance of Chi-square ns

TABLE E54

	LOW Subjective Burden	HIGH Subjective Burden
Lack of volition NO	26	42
YES	43	89

Significance of Chi-square ns

TABLE E55

	LOW Subjective Burden	HIGH Subjective Burden
Manic behaviour NO	55	86
YES	14	47

Significance of Chi-square ns

TABLE E56

	LOW Subjective Burden	HIGH Subjective Burden
Mood changes NO	48	74
YES	21	61

Significance of Chi-square $p<.05$

TABLE E57

	LOW Subjective Burden	HIGH Subjective Burden
Poor temper control NO	31	35
YES	38	99

Significance of Chi-square p<.01

TABLE E58

	LOW Subjective Burden	HIGH Subjective Burden
Callous/uncaring behaviour NO	51	76
YES	17	58

Significance of Chi-square p<.05

TABLE E59

	LOW Subjective Burden	HIGH Subjective Burden
Social withdrawal NO	39	49
YES	30	84

Significance of Chi-square p<.01

TABLE E60

	LOW Subjective Burden	HIGH Subjective Burden
Depressed mood NO	32	46
YES	37	89

Significance of Chi-square ns

TABLE E61

	LOW Subjective Burden	HIGH Subjective Burden
Suspicious behaviour NO	52	81
YES	17	52

Significance of Chi-square p<.05

TABLE E62

	LOW Subjective Burden	HIGH Subjective Burden
Hostile behaviour NO	54	82
YES	15	55

Significance of Chi-square p<.01

TABLE E63

	LOW Subjective Burden	HIGH Subjective Burden
Anxiety NO	34	43
YES	34	92

Significance of Chi-square $p<.05$

TABLE E64

	Low FB (0-2)	Medium FB (3-5)	High FB (6-8)	TOTALS
Low SB (0-2)	37	7	2	46
Medium SB (3-4)	93	32	1	126
High SB (5-6)	146	108	26	280
TOTALS	276	147	29	452

RELATIONSHIP BETWEEN SUBJECTIVE BURDEN AND FAMILY BURDEN
TABLE E65

APPENDIX 2

ADDITIONAL RELIABILITY DATA

A supplementary study was carried out in which a subset of the questionnaire was administered on two separate occasions. Between 7 and 10 days after the relative responded to the questionnaire, he/she was re-interviewed by another interviewer who was blind to the results of the first interview.

The test-retest interval was chosen to try to ensure that real changes in the patient were unlikely but at the same time to reduce the likelihood that respondents would remember their previous responses and simply repeat them. This study, carried out at the Western General Hospital in Edinburgh, was on referred patients post head-injury. There were 9 useable cases (6 male, 3 female) with a mean age of 31.2 years. Average PTA duration was 26.5 days and all were at least 10 months post-injury (mean 15.2 months).

These data were collected as part of the development a revised questionnaire and data are only available on some items from the original questionnaire. Bearing in mind that a previous exercise provided evidence of good consensual agreement, on the whole these further data are reassuring.

NOTE: n/a = no data available on this variable

k n/a = kappa could not be calculated as there was only one non-empty row or column. Where kappa could not be calculated, the number of disagreements may be useful.

	Kappa	Number of disagreements
Physical independence	n/a	
Loss/restricted mobility	n/a	
Weakness	n/a	
Sight problem	.77	1
Hearing problem	1.00	0
Loss of sense of taste	1.00	0
Loss of sense of smell	1.00	0
Poor sense of balance	1.00	0
Dizzy spells	1.00	0
Fits (seizures)	1.00	0
Headaches	1.00	0
Intolerance of noise	1.00	0
Tiredness	1.00	0
Slowness (physical)	.77	1
Often feels unwell	n/a	
Tense/anxious	1.00	0
Restless/wandering	n/a	
Poor sleep	1.00	0

Nightmares	n/a	
Demands attention	n/a	
Impatience	.50	2
Irritability	1.00	0
Easily angered	1.00	0
Threats or gestures of violence	n/a	
Physical violence	1.00	0
Excessive smoking	n/a	
Easily affected by alcohol	n/a	
Excessive drinking	n/a	
After drinking:		
argumentative	n/a	
threatened violence	n/a	
physical violence	n/a	
Trouble with the law	n/a	
Upset by changes to routine	n/a	
Needs tidiness	n/a	
Suspicious/mistrustful	n/a	
Bossiness	n/a	
Nosey/interfering	n/a	
Odd behaviour/ideas	n/a	
Problems with		
Speech articulation	.77	1
Expressive language	.36	2
Holding a conversation	n/a	

Understanding speech	n/a	
Following conversation	.73	1
Poor memory	k n/a	0
Poor concentration	-.17	3
Excessive talking	n/a	
Laughing for no reason	n/a	
Laughing for too long	n/a	
Difficulty behaving in company	n/a	
Quiet/withdrawn in company	n/a	
Avoids company	n/a	
Changes in sex life	1.00	0
Attitude to sex changed	n/a	
Sexual capabilities changed	n/a	
Difficulty in washing/ dressing/toileting	.77	1
Dresses wrong way (e.g. back to front)	n/a	
Less concern with cleanliness etc	n/a	
Enuresis	n/a	
Clumsy (knocks things over)	n/a	
Bumps into things	n/a	
Always accompanied indoors	1.00	0

Unable to be in charge of household	n/a	
Always accompanied outdoors	1.00	0
Loss of interest	n/a	
Childish behaviour	1.00	0
Mood changes	1.00	0
Depressed	.77	1
Worries about future	n/a	
Refusal to admit difficulties	n/a	
Personality change	k n/a	0

SUBJECTIVE BURDEN

For Subjective Burden, which was rated on a 7-point scale, kappa was not used. For this variable, Pearson's r=.96 (p<.001).

APPENDIX 3
FOLLOW-UP QUESTIONNAIRE
VERSION FOR SPOUSE/COHABITEE

1 Case	New case/Old case
2 Sample	Main sample/Other
3 Follow-up	3 month/6 month/ 12 month/Other
(specify)	
4 Sex	Male/Female
5 Marital status	Single/Married Cohabiting/Separated Divorced/Widowed/N.K.
(A15)	
6 How long have you been married/ living together?	________
Years	
(A16)	
7 Note any complications if mentioned spontaneously: e.g. previous marriages, divorce proceedings, etc.	________
Years	
*8 Age of patient (check if necessary)	________
Years	
(A34)	
9 Age of informant	________
Years	
*10 Circumstances of injury: give any available details (Note: some information may be available from items A4 and A5)	
*11 Location	In Home/At work RTA Pedestrian RTA passengers RTA driver/Sport Other (Specify)/N.K.
*12 Cupability (Informant's estimation)	Clearly patient's clearly a specific otherperson/ Uncertain/N.K.
*13 Details of complicating events (e.g. fatalities, others injured, drunk)	
*14 Is there a possibility of a compensation/insurance claim?	Yes (Specify)/No/N.K.
15 (If yes to 14) Has this been settled yet? (Give any available details)	Yes/Still pending/N.K./ N.A

NOTE:If compensation/insurance claim is still pending at 3 month follow-up, ask about progress at susequent follow-up

SYMPTOMS/BEHAVIOURAL DISORDERS
TYPE 2 BURDEN

16 For how long was your H/W in hospital? No. of weeks
Still in hospital? Yes/No
17 Is your H/W physically able to get about by himself? Yes, independently
Yes, with stick/crutch
Confined to wheelchair
Confined to bed/ N.K./N.A.

As a result of the accident, does your H/W suffer from....
18 Paralysis)
19 Loss/restricted mobility) Specify limb(s)
20 Weakness) affected
21 Disorder of sight
22 Disorder of hearing
23 Loss of taste
24 Loss of smell
25 Poor sense of balance
26 Dizzy spells
27 Blackouts
28 Fits (seizures)
29 Headaches
30 Ringing in the ears
31 Other noises in the head
32 Hearing voices in the head
33 Is he troubled by too much noise now?
34 Does he easily become tired now?
35 Has he slowed down physically
36 Does he often feel unwell?
37 Does he often feel anxious or tense?
38 Has he become restless/wandering since the accident?
39 Does he have difficulty sleeping?
40 Does he often have nigtmares
41 Does he demand a lot of attention?
42 Does he often become impatient
43 Is he irritable now?
44 Does he become angry more easily than before?
45 Doea he ever make threats or gestures of violence?
46 When angry, is he ever physically violent?
47 Does he smoke excessively now? (if so, how many per day?)
48 Is he easily affected by alcohol now?
49 Has he been drinkinng excessively since the accident?
50 After drinking.... does he become argumentative?
51 .... does he threaten violence?
52 .... is he physically violent?
53 Has he been in trouble with the law since the accident?
54 Is your H/W upset by changes to routine now?
55 Does he feel a need to keep things tidy now?
56 Has he become suspicious or mistrustful of people?
57 Does he try to tell people what to do?
58 Has he become nosey or inclined to interfere in other's affairs?
59 Does he ever behave oddly or express odd ideas?

60 Does he have difficulty in speaking now? (e.g. slurred speech stammer)

61 Does he have difficulty expressing himself now? (getting through to others, finding the right word)

62 Has he any difficulty in holding a conversation?

63 Does he have dificulty in understanding spoken instructions?

64 Has he any difficulty in following a conversation?

65 Is your H/W's memory worse than before the accident? NOTE: Whether 64 is answered yes or no, use Memory Checklist to check/amplify answer

66 Does he have trouble concentrating? (Reading a paper or book, or watching TV)

67 Does he talk to much now?

68 Does he laugh for no reason at all?

68A Are there times when he keeps laughing for too long?

69 Does he have difficulty behaving in company?

70 When in company does he become quiet and withdrawn?

71 Does he avoid company now?

72 Has your sex life changed since the accident? If YES to 72, ask 73/74

73 Has his attitude to sex changed?

74 ....have his sexual capabilities changed?

75 Has your H/W any difficulty in washing, dressing and toileting himself?

76 Does he sometimes put clothes on the wrong way? (e.g.back to front)

77 Does he show less concern about being clean and tidy?

78 Are there problems with bed-wetting or wetting himself at other times?

79 Does your H/W sometimes knock things over know?

80 Does he sometimes bump into things?

81 Does someone always have to stay in the house with him to look after him?

82 Does someone always have to take charge of the household because your H/W is unable to do so?

83 Does someone have to go out with him when he goes out?

84 Does he need nursing or physical care at home?

85 Has caring for your husband been physically tiring?

86 Overall, do you feel that you are unable to look after him at home?

87 Is physical nursing help required?

88 ....or is help in coping with his behaviour required?

89 On whom does the main responsibility of caring for your /W fall?

Informant
Other(s)
N.K./N.A.

Is there anyone else to help? (specify)

91 Has your H/W lost interest in things going on around him?

92 Does he sometimes behave childishly?

93 Is he prone to quick changes of mood now? (e.g. Suddenly changing from being happy to being depressed)

94 Does he get depressed now?

95 Does he worry about the future?

NOTE on 94/95: Probe for causes of anxiety/depression
Loss of interest
Decline in memory intellect
Loss of indepenence
Loss of emotional control
Any other major problems mentioned

96 Has he ever talked about suicide?
97 Has he ever attempted suicide or deliberately injured himself
98 Does he refuse to admit difficulties now?
99 Has your H/W's personality changed since the accident/lastinterview? (If so, probe and specify).
100 Are their any other changes in your H/W since the accident which we have not covered? (if so, specify)
101 Does he ever complain about his symptoms/difficulties?
102 (If yes to 101) which ones does he complain about? (Specify)
103 Has your H/W's physical state improved since he came out of hospital/since last interview?
104 Has his emotional state improved since he came out of hospital/since last interview? ("nerves", anxiety, depression)
105 Has his behaviour improved since he came out of hospital/since his last interview?
106 What (if any) are the main improvements you have noticed?
(Specify)
107 Overall, how much strain/distress have you felt because of changes in your H/W since the accident?

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

108 Which changes have been most distressing for you?
1)
2)
3)
Other)
109 How have you coped with the changes in your H/W since the accident? (Specify). (i.e. COPING STRATEGIES)
110 INTERVIEWER'S ASSESSMENT of informant's general attitude to patient. (Specify).

EFFECTS ON THE HOUSEHOLD TYPE 1 BURDEN
(HOUSING and household composition - nor reproduced)

Family routine and Health of Family

166 Has anyone in the houshold had to stay away from work to look after your H/W? (If yes, specify)	No Occasionally Yes, 14 days + Yes,permanently N.K. N.A.

167	Has anyone in the houshold had to stay away from school to look after your H/W? (If yes, specify)	No Occasionally Yes, 14 days + Permanently N.K. N.A.
168	Has the houshold routine been upset since your H/W's injury?	No Yes (specify) N.K.
169	Have you had to change your social or leisure habits since the accident... because of your H/W's behaviour?	No Yes N.K. N.A.
170	or............for some other reason?	No Yes N.K. N.A.
171	Have you H/W's leisure activities changed since the accident?	No Yes(s) N.K. N.A.
	What does your H/W do in his leisure time? Where does he go? Who does he go with? How often in the week does he go out?	
172	Have your own leisure activities changed since the accident?	No Yes N.K. N.A.
	What do you do in your leisure time? Where do you go? Who do you go with? How often in the week do you go out?	
173	Have any children in the house taken over tasks that your H/W used to do?	No Yes (specify) N.K. N.A.
174	Have any children in the house been adversely affected?	No Yes (specify) N.K. N.A.
175	Has your own health suffered as a result of caring for your H/W?	No Yes (specify) N.K. N.A.
176	How do you estimate your own health now?	Good Fair/average Poor N.K. N.A.

177	How often have you seen your doctor in the last 3 months?	Not at all Infrequently Regularly N.K. N.A.
178	(If regularly) What is the main trouble? (Specify)	
179	What is the health of other household members like?	Good Fair/average Poor N.K. N.A.
180	Does any family member (excluding patient) suffer from long-term physical or mental illness?	No Yes (specify) N.K. N.A.
181	(If applicable) Do you think that any illness in the family has been caused or made worse by the strain of caring for your H/W?	No Yes (specify) N.K. N.A.

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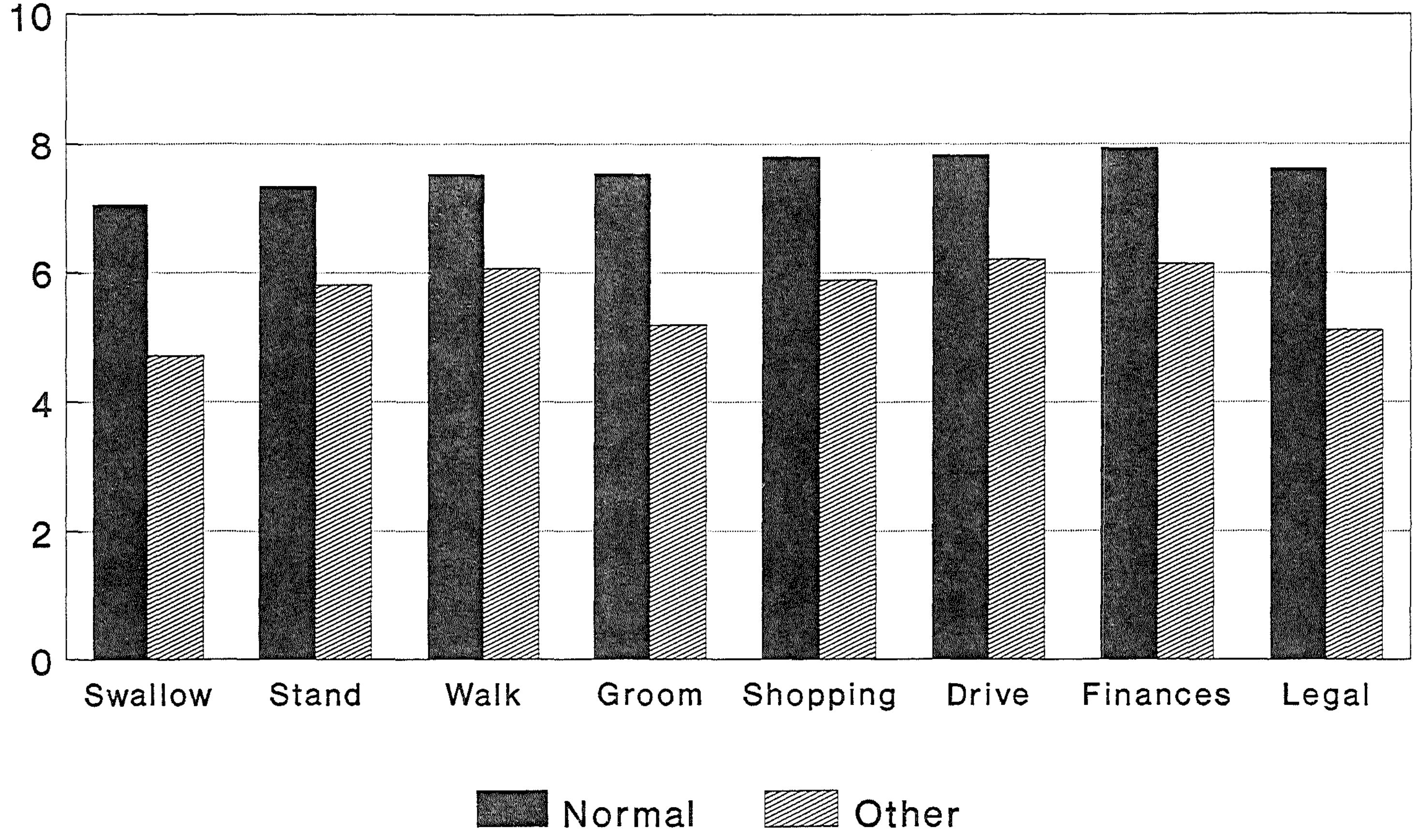
FIGURES 1–5 IN ORDER AS DESCRIBED IN TEXT (CHAPTER 8).

ADLs by LEARNING

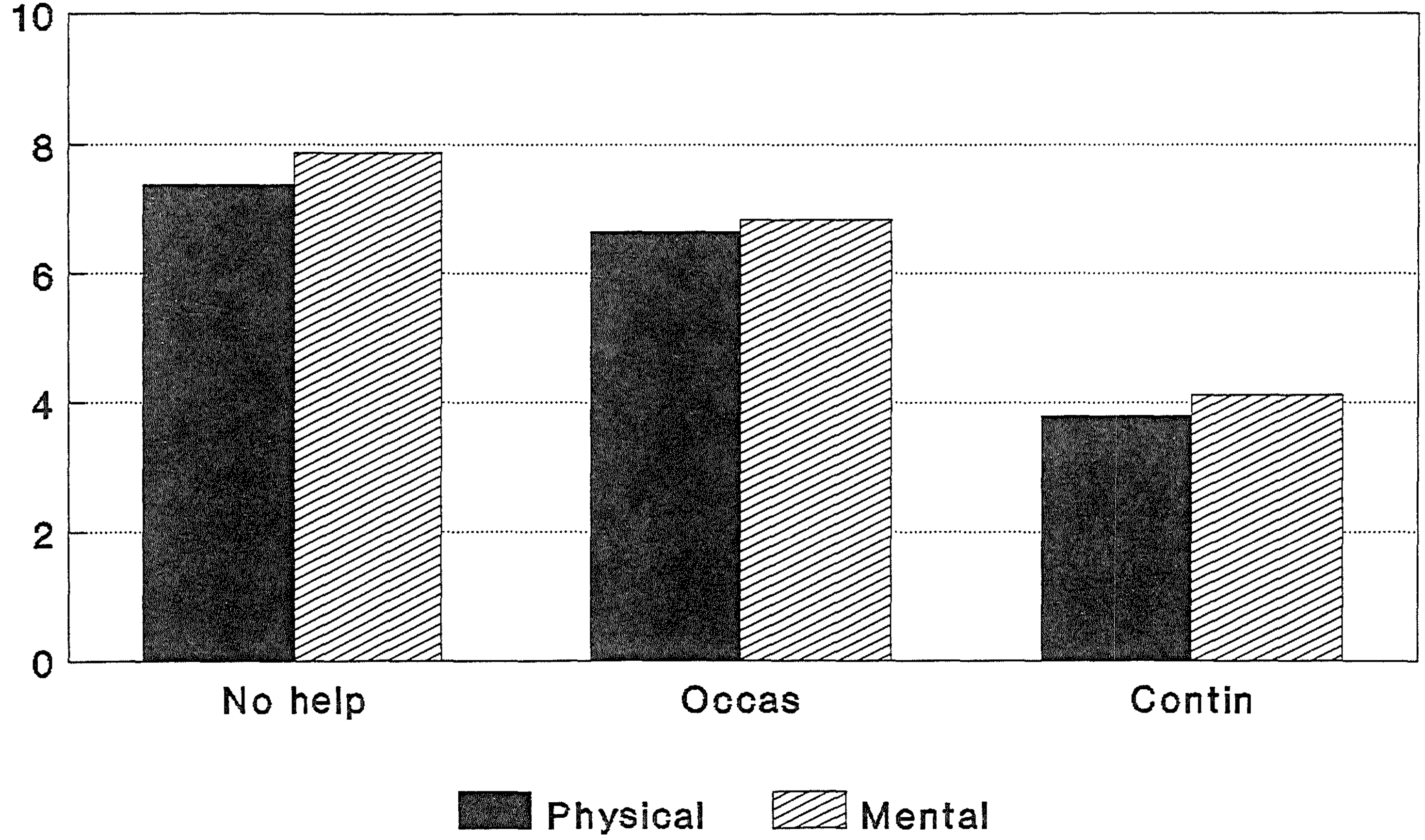
Various items x LRN3



All p .000

AMOUNT OF HELP NEEDED

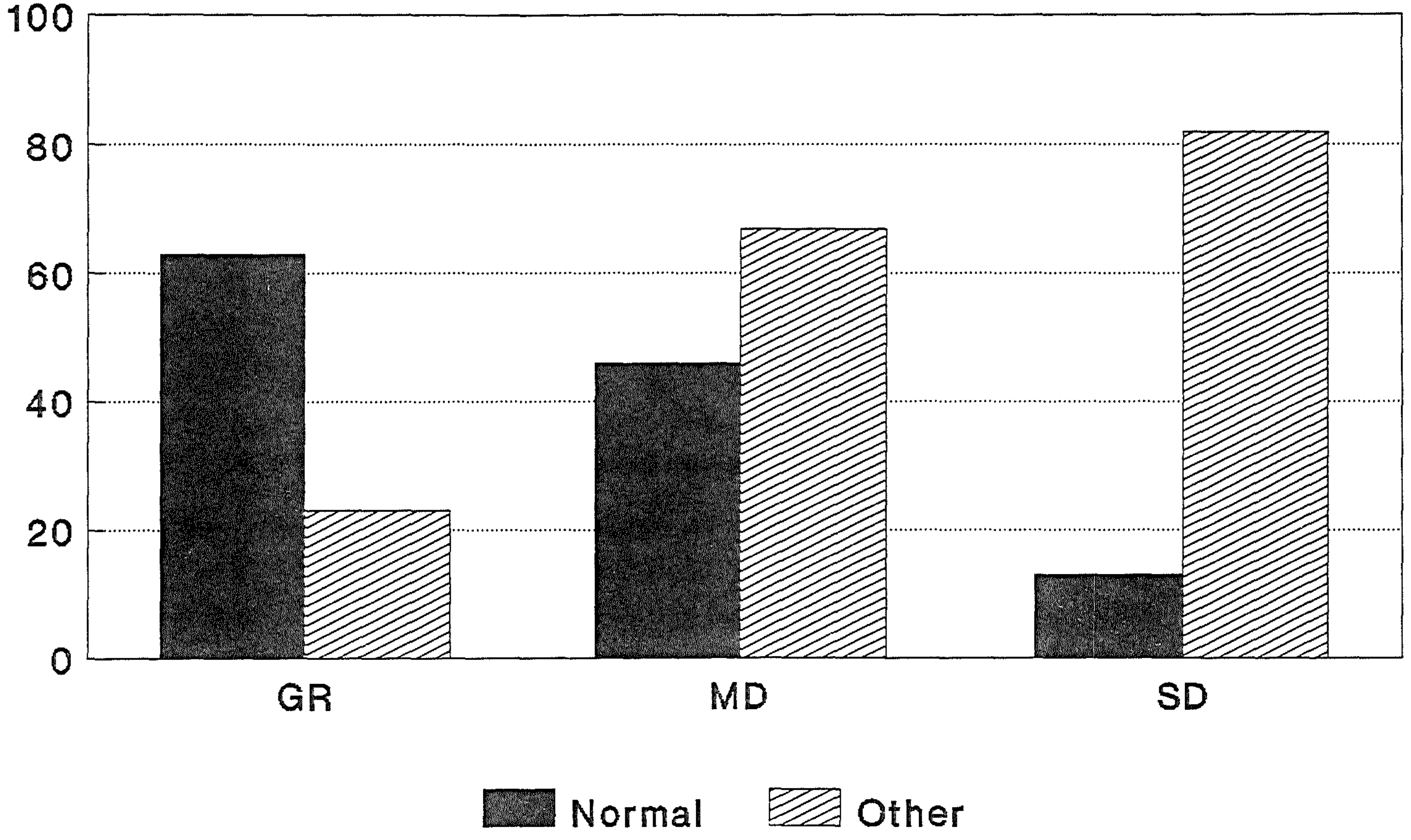
Relationship to learning ability



ANOVA PHYSICAL p.000 MENTAL p.000

RELATIONSHIP TO G.O.S.

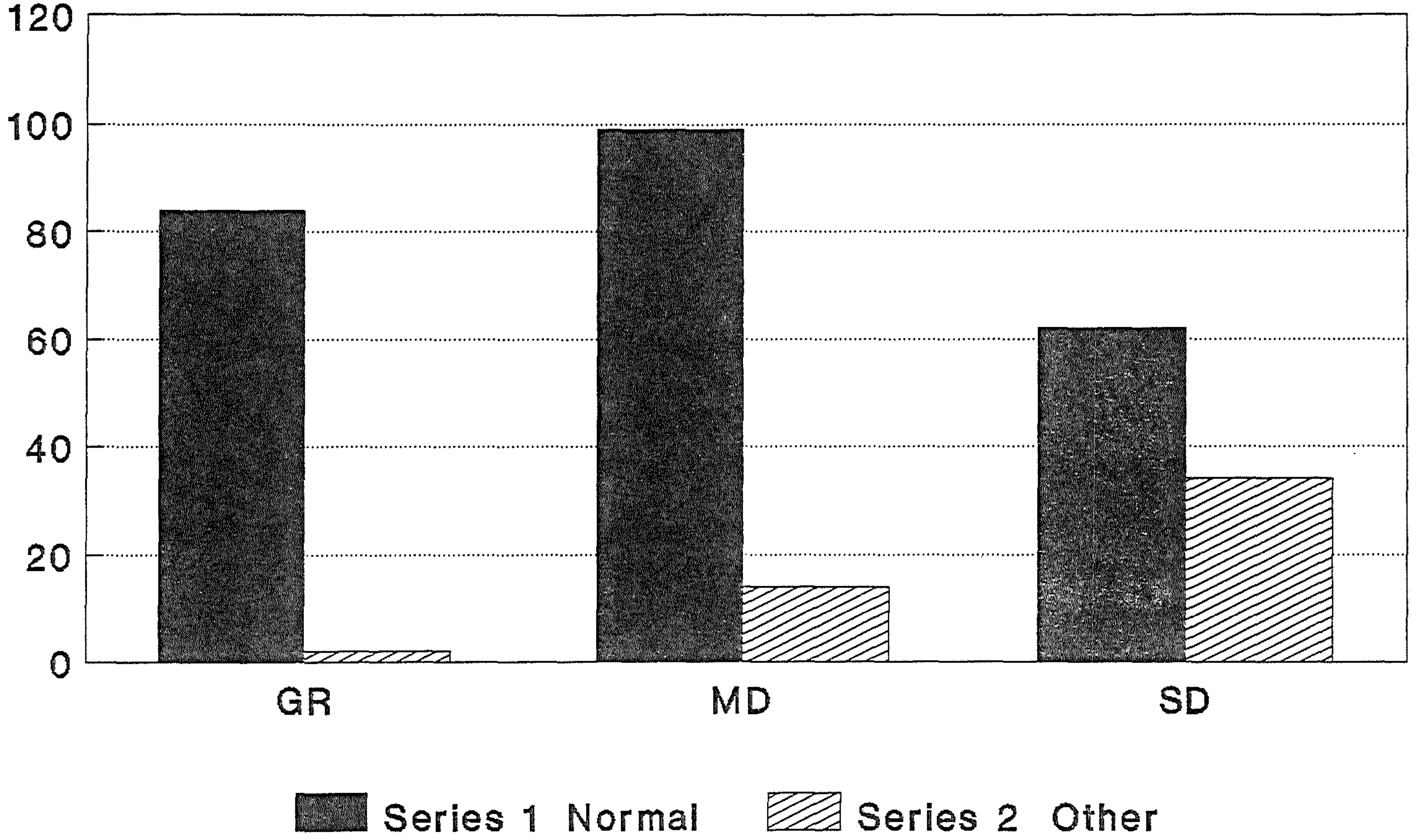
WALKING



p. 0000

RELATIONSHIP TO G.O.S.

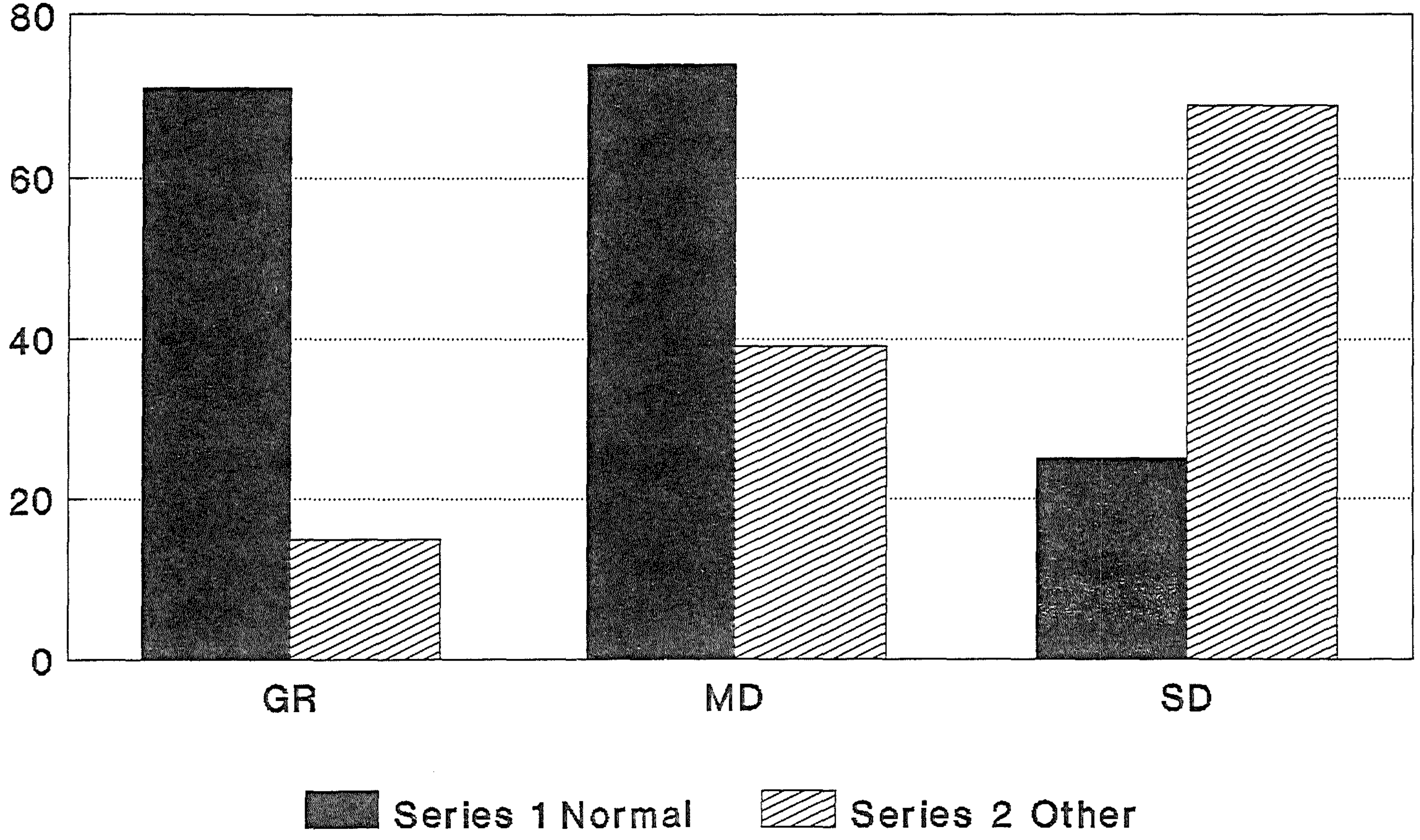
Sphincter



p .0000

RELATIONSHIP TO G.O.S.

Standing



p. 0000

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The short-term outcome of severe blunt head injury as reported by relatives of the injured persons

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SUMMARY A close relative of 55 severely head injured adults (post-traumatic amnesia $\geqslant 2$ days) was interviewed 3, 6 and 12 months after injury to obtain information about psychosocial changes in the patient. The problems most frequently reported were emotional disturbances, poor memory, and subjective symptoms, with physical disability much less common. The amount of stress experienced by relatives did not diminish between 3 and 12 months, and was related to the incidence of mental and behavioural changes in the patient. The question of whether or not compensation was being claimed did not appear to influence the outcome.

Improvements in medical care have made it increasingly likely that patients with severe blunt head injuries will survive. However, a considerable number will remain handicapped and these place a burden on their families and a demand on rehabilitation services.[1-4] While much research has appeared on cognitive deficits, especially memory deficits,[7] there has been less emphasis on the broader spectrum of "psychosocial" changes which may follow head injury. These psychosocial sequelae of head injury include cognitive, emotional and behavioural changes and their effects on family, leisure and occupational life. Reports on the severely injured patient's physical and mental state, however, have stressed the importance of mental changes and in particular personality change. Fahy *et al*[6] found "psychiatric symptoms" in 17 out of 22 cases who had post-traumatic amnesia (PTA) of more than three days. Thomsen[7] not only found personality change in 42 out of 50 cases but noted that patients often lack insight, and for this reason researchers have often interviewed relatives to obtain information about changes in the patient.

Relatives of the brain injured often experience stress,[8 9] although parent–child relationships have been considered to be more resilient than husband–wife relationships.[7 10] The mental changes in the patient following injury, especially personality changes and memory deficits, tend to cause families more difficulty than physical disability.[2 4 7 11] Relatives may deny disability initially and go through an adjustment process analogous to grieving;[12] and relatives may take some time to realise the full extent of the changes in the patient.[13]

The studies mentioned above have been concerned largely with the presence of difficulties and disabilities in the patient and the effects of these on close relatives. Other studies have assessed outcome in functional terms (resumption of activities, especially work), although large-scale follow-ups which report nearly all patients returning to work may include many cases with very minor injuries.[14] Oddy *et al*[15] report that almost half of their "severely" injured patients had resumed full-time work, and another 15% part-time work, only four months after injury and that all of these had resumed work at the same level as before injury. However, it must be noted that the sample of Oddy *et al* was young (80% under 25 years of age), with more cases from the upper than lower social strata and that half the cases had PTA of seven days or less, all of which make a good outcome more likely. Many of the previous studies are unsatisfactory and Oddy *et al*[15] noted that it was often difficult to draw clear conclusions owing to inadequate specification of selection criteria for patients, and inadequate description of study populations, especially with regard to severity. Accordingly, the present authors aim to provide data on the mental, physical and behavioural

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changes observed in a well-documented group of patients. The observers were close relatives of the injured persons and were interviewed at 3, 6 and 12 months after injury and asked to report changes which had occurred in the patient consequent on the injury. Two general questions are posed: (a) what changes in the patient are most frequently observed in the 12 months following injury? and (b) which particular changes are reported in cases where the caring relatives experience stress?

The data presented here are based on part of a continuing and wider study of the psychological and social consequences of severe blunt head injury, some reports of which have already been published.[4, 17]

Method

Patients

Fifty-five cases (46 male) aged 16–60 years (mean 35·7, SD 14·3) with severe blunt head injury constituted the sample. "Severe" injury was defined by at least two days post-traumatic amnesia (PTA) and "blunt" injury was defined as follows: those with penetrating localised wounds were excluded but all other head injuries, including those with depressed fractures, were admitted to the study. Patients known to have previous neurological disease or damage were excluded. The present sample was drawn from the Institute of Neurological Sciences (INS) in Glasgow, which is a secondary facility serving the West of Scotland, and patients are transferred there for investigations and treatments not available at the referring hospitals. The fact that the sample is drawn from a secondary facility necessitates as full a description as possible of demographic and clinical indices to make clear the nature of the sample. Figure 1 and tables 1–4 provide such data. As defined by PTA the sample is a very severely injured one with only 12 out of 55 cases (22%) having PTA of 2–7 days and the median value for PTA being 21 days. It will also be noted that the lower social classes are over-represented in comparison with the population of the catchment area of the present research, that is, the Clydesdale conurbation. This over-representation of the lower social classes is characteristic of the head-injured population.[18] Nineteen patients were single, 33 were married or cohabiting, and one each was separated, divorced, and widowed.

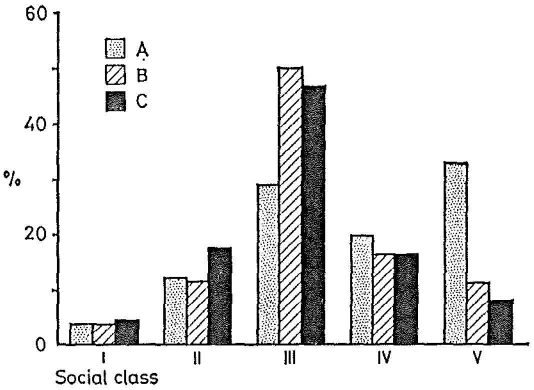

Fig 1 *Social class distribution: percentage of patients (A) in each of the Registrar General's social classes compared with the general population of the Clydeside conurbation (B) and the United Kingdom as a whole (C).*

Table 1 *Location or cause of injury*

Road traffic accident	26
Accident at work	4
Accident at home	1
Assault	11
"Fell"	7
Other	6
Total	55

Table 2 *Major complications present*

Skull fracture only	13
Haematoma only	11
Both skull fracture and haematoma	18
Neither	13
Total	55

Table 3 *Whether neurosurgical operation was carried out*

Yes	28
No	27
Total	55

Table 4 *Duration of post traumatic amnesia (PTA)*

2–7 days	12
8–14 days	6
15–28 days	14
1–2 months	12
2–3 months	5
Over 3 months	4
Total	53*

* In 2 cases no reliable estimate of PTA could be obtained.

Procedure

A close relative of each patient was interviewed three times. Interviews were carried out at 3, 6 and 12 months post-injury. Relatives were asked to report changes in the patient which emerged after injury and which were present either since injury or since the previous assessment, whichever was the more recent. Interviewees who bore a major day-to-day responsibility for care of the patient (or would have if the patient was not in hospital), were included (see table 5). The structured interview schedule included questions about the patient's physical and mental state, behaviour and self-care ability. This was based on the methods used by Grad and Sainsbury[19] and Hoenig and Hamilton[20]: changes observed in the patient were designated "objective" burden and the amount of strain or distress experienced by the relative as arising from these "objective" changes was designated "subjective" burden.

Table 5 *Relationship of informants to patients*

	3 months	*6 months*	*12 months*
Wife	28	27	27
Husband	3	4	4
Mother	10	12	12
Father	5	6	5
Other relative	8	6	5
Non relative	1	0	2
	55	55	55

Note: While every attempt was made to interview the same informant at each follow-up, this did not always prove possible. However, all informants bore a major day-to-day responsibility for care of the patient.

The interview schedule was designed to assess problems reported in the literature or encountered during the authors' clinical and research work with head injured patients. There were 90 items which made as comprehensive as possible a survey of the difficulties which may be observed in head injured patients, that is objective burden. Subjective burden was assessed using a simple seven-point rating scale ranging from: (1) "I feel no strain as a result of the changes in my spouse/relative" to (7) "I feel severe strain as a result of the changes in my spouse/relative."

It is important to note that only *changes* (that is the appearance of mental or physical deficits or abnormal behaviours in the patient) occurring since injury were recorded. Moreover, ratings of both objective and subjective burden refer explicitly to the relative's view of the situation. Reliability of a pilot version of the questionnaire was assessed by having two researchers interview 20 relatives: 10 relatives were interviewed by one researcher and 10 by the other with both present. Disagreement occurred only where the degree rather than presence of change was recorded and questions where such disagreements occurred are not included in the present analysis.

Results

Table 6 *The ten problems most frequently reported by relatives as being present in the patient (per cent reporting)*

	3 months	*6 months*	*12 months*
Slowness	86	69	67
Tiredness	82	69	69
Irritability	63	69	71
Poor memory	73	59	69
Impatience	60	64	71
Tension and anxiety	57	66	58
Bad temper	48	56	67
Personality change	49	58	60
Depressed mood	57	52	57
Headaches	54	46	53

The most frequently reported changes in the patient were mental rather than physical with such difficulties as slowness, tiredness, irritability and poor memory being reported in the majority of cases (table 6). In order to obtain an overall view of the most prevalent difficulties, questionnaire items were divided into seven categories for analysis. These categories (listed below) are arbitrary to some degree, but an attempt was made to reflect common distinctions which are made in the literature and in clinical practice.

(1) The *physical* category included sensory and motor impairment, gait disturbances, fits and poor balance. The most common changes were impairment of vision (usually minor) quoted in 53%, 47% and 42% of cases at 3, 6 and 12 months respectively; and an impairment of balance reported in 49%, 40% and 40% of cases. Paralysis of a limb was relatively uncommon (11%, 6% and 4% at successive follow-ups), and even by 3 month follow-up most patients were independently mobile (see table 7).

Table 7 *Degree of physical mobility*

	3 months		*6 months*		*12 months*	
	N	*%*	*N*	*%*	*N*	*%*
Independently mobile	48	87	50	91	50	91
Independent, but needs stick or crutch	5	9	3	6	3	6
Confined to wheelchair	1	2	2	4	2	4
Confined to bed	1	2	0	0	0	0

(2) The *language* category consisted of dysarthria and dysphasia. The most frequent problems were difficulty in expression (for example word finding or fluency) reported in 47%, 44% and 44% of cases at 3, 6 and 12 months respectively, and dysarthria in 33%, 26% and 29% of cases. In some cases the difficulties were minor and although noted by relatives were not always apparent to the psychologist who assessed the patient. Receptive difficulties were less common (no more than 15% of cases at any follow-up). There was an association between dysarthria and physical disability at 3 months, when five out of the six cases with

paralysis of a limb also had dysarthria. However, at 6 and 12 month follow-ups the number of physically disabled patients was too small to allow reliable resuts to be obtained. Moreover, many patients were reported to have dysarthria or dysphasia but not to have physical disability.

(3) The *emotional* category consisted of loss of emotional control (temper, irritability, etc) and loss of emotional stability (mood swings, depression, etc). Emotional changes were rereported very frequently and were often viewed seriously by relatives. Irritability, for example, was reported in 63%, 69% and 71% of cases at 3, 6 and 12 months respectively. Other difficulties reported in more than half the cases were impatience, tension and anxiety, and depression, at 3 months; and impatience, bad temper, tension and anxiety, depression, and personality change, at both 6 and 12 months. Where bad temper was reported, irritability was also reported but the reverse was not true: it appears that at least some respondents used the former term to denote a greater degree of ill-humour. Even the less frequent items in this area were still reported in a substantial number of cases (for example mood swings were noted in 33%, 38% and 62% of cases at consecutive interviews). Whereas physical and language items almost invariably declined in frequency over time, half the items in the *emotional* group were reported with increasing frequency at consecutive interviews.

(4) Items in the *dependence* group included difficulties in self-care and the need for supervision. Between 20% and 25% "could not be left in charge of the household" even after 1 year but only 17% needed help with washing and dressing at 3 months and only 9% by 12 months. Problems in this area usually declined over time.

(5) The *subjective* category consisted such subjective symptoms as slowness, tiredness, poor concentration, and headaches. These problems were very common, for example 86%, 69% and 67% reported slowness at 3, 6 and 12 months respectively. Around a half reported headaches and over a third reported poor concentration even at 1 year. Nevertheless, difficulties in this area tended to become less frequent over time.

(6) The group of *memory* items included disorientation, omissions, repetitions and other indications of memory lapses. Overall, memory difficulties were reported in 73% of cases at 3 months, 59% at 6 months and 69% at 12 months.

(7) Finally a group of items designated *disturbed behaviour* was formed. This consisted of bizarre or puzzling conduct, including violent and inappropriate social behaviour. Threats of violence and inappropriate social behaviour were reported in less than 20% of cases at each stage. However, the appearance of such phenomena in families where they had previously been absent or markedly less frequent tended to be viewed seriously by relatives. The most frequent changes were the onset of excessive talking (33%, 26% and 27%) and childishness (35%, 35% and 46%). Many of the items in the *disturbed behaviour* category increased or fluctuated in frequency over time with few showing a steady decline.

Changes in sexual adjustment are not considered in detail in this paper because of the difficulty in comparing married or cohabiting patients with those who do not have a partner. However, 15 (48%) of the 31 spouses interviewed reported a change in their partner's sexual behaviour at each follow-up; and where the interviewee was not the spouse there were fewer reports (less than 15%) of a change in "interest" in the opposite sex. Changes in sexual adjustment will be examined more fully in later papers.

In order to obtain a clearer overall picture, the number of difficulties reported in each of the seven categories was calculated and the absolute frequency scaled to give a figure "out of 10". A one way analysis of variance was carried out for each follow-up to test the hypothesis that significantly more changes in the patient were reported in some categoires than others. This hypothesis was confirmed ($p<0{\cdot}01$) for all three follow-up times and Scheffe tests indicated that a higher number of *emotional* and *subjective* items were reported than items in any other category ($p<0{\cdot}01$) at all follow-ups (table 8).

Table 8 *Mean number of difficulties (out of 10) reported by relatives*

	3 months	*6 months*	*12 months*
Physical	1·8	1·6	1·5
Subjective	4·5	4·3	4·5
Language	2·4	2·2	2·1
Emotional	4·6	5·1	5·4
Dependence	1·8	1·5	1·4
Disturbed behaviour	1·4	1·6	1·9
Memory	2·7	2·3	2·7

Next, the level of subjective burden (SB) experienced by relatives was considered. On a scale from 1 (no stress) to 7 (severe stress), the mean SB reported was 3·5 at each follow-up, which approximates to "moderate stress." It is possible that SB experienced by relatives is merely a reflection of the severity of injury sustained by the patient. Duration of post-traumatic amnesia (PTA) was used as an index of severity; and cases were divided into three groups according to the degree of stress (subjective burden) experienced by the relative on a seven point scale as shown in table 9. The length of PTA reported in the three groups was compared by means of analysis of variance. At 3 months there was a highly significant ($p<0.001$) tendency for cases where SB was higher to have longer PTA; at 6 months the differences reached only the 0·05 level of significance; and at 12 months there was a trend which failed to reach statistical significance (table 10).

Table 9 *Division of cases into 3 subjective burden (SB) groups according to the degree of SB experienced by the relative*

		Number of cases		
		3 months	*6 months*	*12 months*
"Low stress"	SB rating of 1–2	17	15	14
"Medium stress"	SB rating of 3–4	22	22	20
"High stress"	SB rating of 5–7	16	18	21

Table 10 *Comparison by means of one way analysis of variance of the duration of PTA in patients whose relatives experience low, medium, or high stress*

	Mean PTA in days		
	3 months	*6 months*	*12 months*
Group 1 (SB=1 or 2)	13·3	14·4	17·7
Group 2 (SB=3 or 4)	24·0	33·9	31·2
Group 3 (SB=5–7)	49·7	38·9	37·7

One way analysis of variance: probability of F0·0002, 0·0359, 1013.

Note The changes in PTA which occur over time are due only to changes in reported SB and consequent changes in the composition of the 3 SB groups. Only one value of PTA was used for each case.

The relationship between objective and subjective burden was examined by means of analysis of variance. Again cases were divided into three groups according to the degree of stress (subjective burden) experienced by the relative as rated on a seven point scale, as shown in table 9. To determine whether relatives who reported higher degrees of stress (SB) also observed more changes in the patient than low stress relatives, the three SB groups were compared on the seven problem areas by means of one way analysis of variance. A significance level of 0·01 was used to reduce the risk of type 1 error.

For almost all problem areas and follow-ups the trend is that the higher the perceived stress, the more changes in the patient are reported although this is not always statistically significant (fig 2). No significant differences were found between the three SB groups on the number of changes in the physical and language categories. Significant differences were found between SB groups on the number of subjective, emotional and disturbed behaviour changes at all follow-ups. The differences between SB groups on the number of

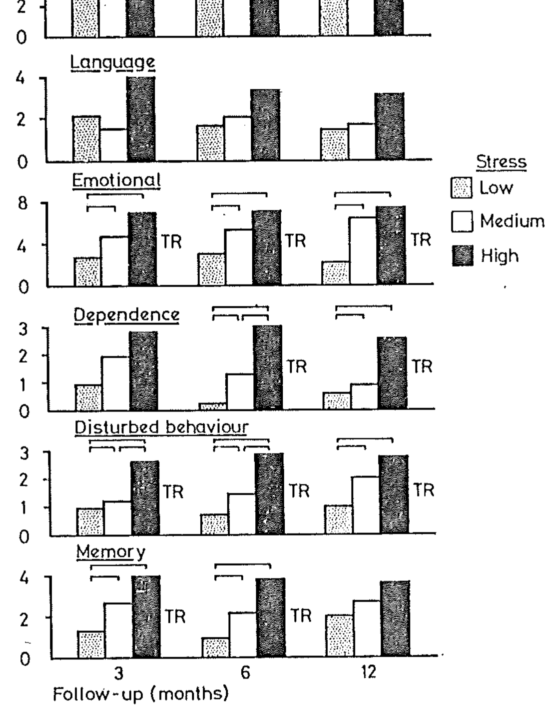

Fig 2 *Mean number of changes in the patient reported by relatives under low, medium and high stress. Results are given for the seven problem areas at each follow-up time. "TR" (trend) denotes a significant ($p<0.01$) one way analysis of variance across groups; and pairs of groups which are bracketed together differ significantly ($p<0.01$) from each other.*

memory changes were significant at 3 and 6 months; and the differences between SB groups on the number of dependence changes were significant at 6 and 12 months.

Where the one way analysis of variance was significant, all three groups did not always differ significantly. For example, "low stress" relatives reported fewer emotional changes in the patient than "medium" or "high" stress relatives, but these last two did not differ significantly at all three follow-ups.

Finally, the role of compensation claims was considered as a possible factor in elevating the number of difficulties reported. From the sample of 55 cases, two subsamples of 21 were chosen. These were cases who had consistently, at each follow-up, expressed the view that they had grounds to pursue a claim, or that they had no such grounds. Cases where there was some doubt and the two cases where the claim was settled were excluded. The two groups were compared in three ways. Firstly, a series of *t*-tests were carried out comparing the number of reported changes in the patients in each of the seven problem areas already outlined. None of the 21 comparisons reached the 5% level of significance. Secondly, there was a tendency for cases claiming compensation to be more severely injured in terms of PTA (claim group: mean PTA=39 days; no-claim group: mean PTA=18 days) although because of large variances this failed to reach the 5% level of significance on the *t*-test. Thirdly, a series of analyses of variance were caried out, using PTA as covariate. Again there were no significant differences at the 5% level between claim and no-claim groups.

Discussion

Our results indicate that for a group of adults with severe blunt head injury the problems most frequently reported by relatives are emotional changes, poor memory and subjective symptoms such as slowness and tiredness. Physical difficulties are less frequent and all but five out of 55 cases were independently mobile without the need of a stick, crutch or wheelchair by 6 months after injury. There was a tendency for certain types of problem, particularly emotional difficulties to be reported more frequently at later follow-ups: for example, bad temper was reported in 48% of cases at 3 months and 67% at 12 months; and mood swings were reported in 33% at 3 months and 62% at 12 months. It may be that these changes are a reaction to disability, that is, they stem from frustration at not being able to resume normal activities and at not being free from symptoms; or it may be that they are a primary result of the injury and although present from the time of injury are not observed or admitted by the relatives for some time, as suggested by Romano[12] and Lezak.[13] To try to resolve this issue, amongst others, we are at present collecting data on a group of paraplegic patients: these are patients whose lives have been threatened and who have been disabled by trauma but who have escaped brain injury. When these data are available we hope to return to the issue.

Compensation did not play a significant role in elevating the number of changes reported in the patients. There was a slight (but statistically insignificant) tendency for those claiming compensation to have had more severe injuries. However, whether or not this is allowed for (by means of covariance analysis) there are no statistically significant differences in the number of changes reported in cases where compensation is claimed and those where it is not claimed. Indeed, the differences in the number of changes reported in the two groups is very small and occurs in both directions.

The mean level of stress experienced by relatives was the same at 3, 6 and 12 months, post-injury which is consistent with the finding of Oddy *et al*,[11] that stress levelled off sometime between 1 and 6 months. The relationship between the severity of the patient's injury (as assessed by PTA), and the degree of stress experienced by the relative weakened over time: stress in relatives is not a simple reflection of severity of injury. However, there is an association between stress experienced by the relatives and certain types of reported problems in the patient. The specific relationships have already been outlined, but in general, mental and behavioural changes in the patient are associated with significantly increased stress in the relative whereas physical and speech/language difficulties are not. It should not be assumed that there is a direct causal relationship between reported changes in the patient (objective burden) and the stress which the relative suffers and attributes to these changes (subjective burden). Both types of burden are assessed on the basis of a relative's report and there may well be an interplay between stress in the relative and the relative's observation of the patient whereby the observations are coloured by the degree of stress experienced. For this reason the conclusion of Oddy *et al*[11] that personality change is a "source" of stress for relatives should be treated with caution since they used a method similar to ours in that reports of patients' problems and relatives' stress were both obtained from relatives. However, to the extent that we have found a link between reported mental and behavioural changes in the patient and stress in the relative our findings are in broad agreement with previous studies[7 11] as well as our own previous work.[2 4] This has important implications for rehabilitation. The fact that an association exists between reports of mental and behavioural changes in the patient and stress in the relative indicates that in those families most in need of help, rehabilitationists will find that mental and behavioural problems are the primary concern.

In conclusion, we have provided a description of the problems of adults with severe blunt head injury in the 12 months after injury as seen by close relatives. An account has also been given of those types of problem most associated with stress in the relative. Future analysis will describe the resumption of work and other activities in the same group of patients and the link between the persistence of the problems discussed in this paper and the resumption of normal activities.

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Post-concussional symptoms, financial compensation and outcome of severe blunt head injury

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SUMMARY Two groups, each of 21 cases of severe blunt head injury, were compared. Patients in one group were pursuing claims for financial compensation while patients in the other were not. Patients were assessed on cognitive tests, and both patients and relatives were interviewed at 3, 6 and 12 months after injury. There were few differences between claimants and non-claimants: post-concussional symptoms were common in both, cognitive performance was equal, and the reports given by relatives of changes in the patients were very similar. However, the reports given by patients themselves differed with claimants reporting slightly more symptoms than non-claimants.

It is generally agreed that severe blunt head injury may result in significant distress for both the injured and their families. A variety of cognitive deficits have been demonstrated particularly in memory and concentration and generally in the more fluid, less highly practised abilities.[1–5] The subjective, emotional and behavioural changes which may occur in the patient following injury have also been described, as have the effects of these "psychosocial" changes on family life.[6–11] However, the extent to which these sequelae are related to the nature and the severity of the original injury and the extent to which they are secondary has been less thoroughly explored. Secondary factors may include individual differences in reaction to disability, the availability of social support, and whether or not financial compensation is being claimed. The last mentioned will be considered in this paper, along with the related issue of post-concussional symptoms.

The literature on the role of financial compensation following severe head injury is sparse, but where it has been discussed it has usually been in the context of drawing a distinction between the mildly injured and the severely injured. In the mildly head-injured, a post-concussional syndrome of headache, dizziness, poor concentration and memory, fatigue and irritability has often been attributed to psychological rather than organic factors.[12] However, in a recent review of the evidence, Jennett and Teasdale draw the conclusion that "even brief concussion usually entails some structural damage to the brain" (ref 12, p 259) and that "the damage done by and the symptoms subsequently suffered after mild head injuries are frequently underestimated" (ibid p 263). In particular they noted that neuro-otological and psychological examinations have revealed a high incidence of abnormalities in mildly injured patients who show no abnormal signs on routine clinical neurological examination. Recent work on evoked potentials[13] represents another promising route to exploring this area.

While research of this sort suggests that there may be an organic component underlying post-concussional symptoms, the desire for financial compensation has also been suspected of playing a part. Cook[14] compared two groups of mildly injured cases (mean post-traumatic amnesia less than 30 minutes) and found claimants had more persistent post-concussional symptoms and longer absence from work than non-claimants. However, the fact that these conclusions were based on a response of less than 50% to a postal questionnaire detracts from their value. Cartlidge[15] studied a group of predominantly mildly injured patients and found that those who had an increasing incidence of symptoms as time progressed were more likely to be claiming compensation than those with subsiding symptoms. Cartlidge and Shaw,[16] reporting on the same group of cases, noted that the patients with anxiety and

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depression were more likely to be claiming compensation than those in whom these symptoms were absent.

Miller has argued strongly for a link between claims for financial compensation and symptoms in the mildly head injured. The post-concussional syndrome is "graven on the heart of every claimant for compensation" following mild injury and symptoms nearly always remit on settlement of their claim—"win or lose".[17] Such cases are sharply contrasted with the severely brain-injured where post-concussional symptoms "are conspicuously absent":[18] this absence in the more severely injured cases seems to suggest a non-organic aetiology in the mildly injured. However, Miller's conclusions must be set against a good deal of evidence to the contrary. Merskey and Woodforde[19] found that the prospect of financial gain did not account for the clinical picture in their group of mild injuries, and Kelly[20] has shown that many claimants make good recoveries before settlement while many non-claimants develop post-concussional symptoms. Moreover, Rimel *et al*[21] found high rates of morbidity and absence from work in their sample of patients 3 months after minor head injury, despite an absence of clinical signs, and this finding was not attributable to litigation. The disagreement between Miller's conclusions and others' findings may reflect the fact that Miller's sample was grossly atypical of the head injured population as a whole, consisting wholly of medico-legal referrals.[22] As Cartlidge and Shaw note:—". . . in the context of medico-legal examination (symptoms) are apt to be attributed to attempted deception for the basest of motives, yet how often are they encountered in everyday practice where 'functional overlay' is readily accepted on the basis of anxiety or diminished expectation of performance" (ref 16, p 153). In short, there is some controversy over the aetiology of post-concussional symptoms following mild head injury. The current view seems to be that the role of an organic component may have been underestimated in the past, but that psychological factors including compensation may play some part. There has been less comment in the literature on the link between compensation and symptoms in more severely injured cases. Not only is it evident that there is genuine organic impairment in such cases, but post-concussional symptoms have been thought by some authors to be relatively rare. Miller suggested that post-concussional symptoms are "conspicuously absent" in severe cases and that there is an inverse relationship between the likelihood of accident neurosis and severity of injury.[17 18]

The aim of the present paper is to examine the incidence of post-concussional symptoms and the effects, if any, that claiming compensation has on cognitive and psychosocial recovery during the first year following severe head injury. This is an issue of particular interest to both medical practitioners and clinical psychologists since they are often asked by lawyers to assess the extent of the mental and behavioural disturbance in patients following head injury and also to assess the extent to which such changes are directly attributable to the injury. Group comparison data will be reported to assess the overall significance of compensation in elevating complaints in the severely head injured in the year following injury. This group comparison is based on data collected in the course of a wider study of the psychological and social consequences of severe head injury some reports of which have already been published.[4 10 11]

Method

Patients

Two groups were drawn, by the method described below, from a larger group of 55 patients who, together with their relatives, were the subject of a wide ranging study into the psychological and social consequences of severe blunt head injury. Patients aged between 16 and 60 years were admitted to the study. "Severe" injury was defined by at least 2 days post-traumatic amnesia (PTA) assessed retrospectively and "blunt" injury was taken to include depressed fractures but to exclude penetrating localised wounds (for example, gunshot). Patients known to have pre-existing neurological impairments were excluded. All patients had passed through the neurosurgical unit at the Institute of Neurological Sciences (INS) in Glasgow, which is a secondary facility serving the West of Scotland to which head injured patients are transferred for investigations and treatments not available at primary receiving hospitals.

From the sample of 55 cases obtained in this way two groups, each of 21 cases, were selected. The first group consisted of all those cases in whom a claim for financial compensation was being pursued and which remained outstanding throughout the 12 months of the follow-up. The second group consisted of all those cases in which no such claim was being pursued. In the remaining 13 cases, there was doubt as to whether they had grounds or sufficient evidence to pursue a claim. A description of the demographic and clinical characteristics of the two groups studied is provided in tables 1–5, which indicate *inter alia* that the sample was on the whole very severely injured. More non-claimants had a neurosurgical operation, reflecting differences between groups in the number of haematomas. Previous research[5] has indicated that better cognitive outcome was associated with operated haematomas but this was attributable to shorter PTA in the operated group. In the present study non-claimants tended to have shorter PTA but not to a statistically significant extent ($p > 0{\cdot}05$). Sex and social class distributions were very similar for each group as was the relationship of relatives interviewed to patients. However, claimants were significantly younger than non-claimants

Table 1 *Nature of injury*

	Claim	*No Claim*
Location or cause:		
Road traffic accident	10	6
Accident at work	5	0
Assault	6	3
Other	0	12
	21	21
Major complications:		
Skull fracture only	7	3
Haematoma only	4	3
Both	4	12
Neither	6	3
	21	21
Neurosurgical operation:		
Yes	7	15
No	14	6
	21	21

Table 2 *Duration of post-traumatic amnesia (PTA)*

	Claim	*No Claim*
2– 7 days	5	4
8–14 days	2	4
15–30 days	4	7
31–60 days	3	5
61–90 days	2	1
Over 90 days	3	0
	19*	21

Median PTA is 29·7 days for the claim group and 20·7 days for the no claim group.

*In 2 of the 21 cases in this group, no reliable estimate of PTA could be obtained.

Table 3 *Age, sex and marital status*

	Claim	*No Claim*
Age at injury (mean, SD)	31·2, 12·7	43·2, 12·5
Sex (males, females)	18, 3	18, 3
Marital status:		
Married/cohabiting	12	16
Separated/divorced/ widowed	2	0
Single	7	5
	21	21

Table 4 *Social class distribution: number of patients in each of the Registrar-General's social classes*

	Social class					*Total*
	1	*2*	*3*	*4*	*5*	
Claim	0	3	7	6	5	21
No claim	1	2	4	4	10	21

Table 5 *Relationship of informants to patients*

	3 months		*6 months*		*12 months*	
	Claim	No claim	Claim	No claim	Claim	No claim
Spouse	11	15	11	15	12	15
Parent	7	2	9	3	8	2
Other	3	4	1	3	1	4
	21	21	21	21	21	21

Note: All informants were involved in day-to-day contact with the patients, and where possible the same informant was interviewed at each follow-up.

($p < 0{\cdot}01$) and this difference will be considered in the group comparisons to be reported.

Procedure

Assessments were carried out at 3, 6 and 12 months after injury using a battery of psychometric measures and a brief structured interview asking patients about symptoms which they had noticed since injury. Relatives were also interviewed separately from the patients on each occasion and were asked to report changes in the patient which emerged after injury. All relatives interviewed bore a major day-to-day responsibility for care of the patient.

Results

1. *Psychometric test scores*

Claimants and non-claimants were compared on psychometric test performance on a range of tests: these were tests of Verbal IQ (Mill Hill Vocabulary Scale[23]), Non-verbal IQ (Raven's Progressive Matrices[24]), immediate and delayed verbal recall (Logical Memory Sub-Test from the Wechsler Memory Scale[25]), immediate and delayed visual recall (Rey Picture Test[26]), receptive language (number correct on Part 5 of the Token Test[27]) and expressive language (Word Fluency Test[28]). A series of two-tailed t tests was carried out to determine if there were any differences between claimants and non-claimants. Eight of the 24 comparisons generated in this way were significant ($p < 0{\cdot}05$) and all of these indicated that the claimants had performed better on the tests than non-claimants. However, there was a statistically significant ($p < 0{\cdot}01$) tendency for the claimants to be younger and since this clearly might have an influence on test scores a series of analyses of co-variance was carried out using age as co-variate. When this was done, all but two of the significant differences disappeared leaving only two differences which were significant at the 5% level. With only two out of 24 comparisons reaching the 5% level of significance, it may be concluded that there was no overall difference in psychometric test performance between claimants and non-claimants.

2. *Relatives' reports of patients' syndromes*

A series of analyses was carried out on the information given by relatives about changes in the patients. On the basis of the structured interviews which had been carried out with relatives at each follow-up, we calculated the mean number of changes which the relatives reported in each of seven areas of functioning. This number was scaled as if "out of 10" so that the number of changes reported in each area would be comparable, and the results are summarised in the figure. In both claim and no claim groups emotional and subjective changes were most frequently reported and the profiles of the claim and no-claim groups were very similar indeed. Claim and no-claim groups were compared statistically on each of the seven areas of functioning at each of the three follow-ups. *T* tests indicated that none of the 21 comparisons reached the 5% level of significance (two-tailed). These results fail to provide support for the proposition that the relatives of claimants report more extensive changes in the patients than do relatives of non-claimants. In order to exclude the possibility of a specific difference in respect of post-concussional symptoms, a further analysis was carried out. The numbers of post-concussional symptoms present in claim and no-claim groups were compared using the group of four core post-concussional symptoms suggested by Miller,[17] that is, headaches, dizziness, irritability and poor concentration (table 6). At each follow-up, comparison by Mann-Whitney U test revealed no statistically significant difference.

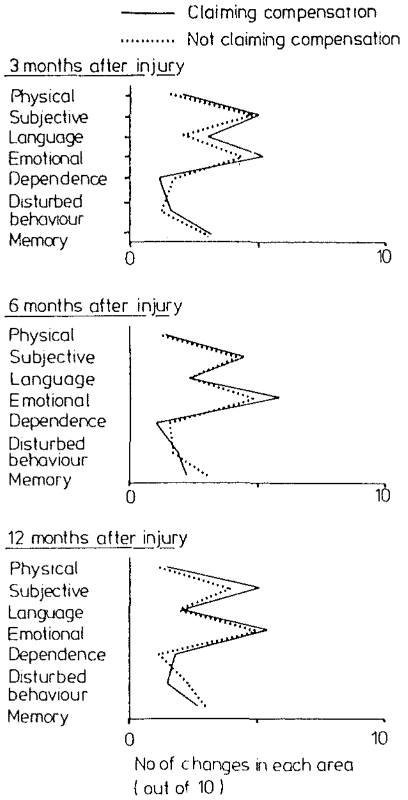

Fig *Mean changes in patients as reported by relatives.*

3. *Patients' reports of their symptoms*

The next series of analyses carried out was on the patients' own responses to the structured interview mentioned above. Firstly, three of the four core post-concussional symptoms were examined (poor concentration, dizziness and irritability). A question about headache had not been included in the patients' structured interview because we had accepted the view—which we now believe to be mistaken—that post-concussional symptoms are rare after severe head injury. The number of these post-concussional symptoms reported by the patients in each group is given in table 7. Claimants tended to report more symptoms than non-claimants, this difference reaching statistical significance on the Mann-Whitney U test ($p < 0{\cdot}05$) at 3 and 12 months follow-up. Next, the total number of symptoms reported by patients from a wider-ranging list of 20 items was calculated. The claim and no-claim groups were compared (table 8). *T* tests indicated that there was a significant difference at each follow-up. When the effects of age and PTA were co-varied out the difference remained significant at the 5% level at all three follow-up times indicating an overall tendency for patients who were claiming compensation to report more symptoms than those who were not claiming.

4. *Return to work*

The numbers of claimants and non-claimants who had returned to work at each follow-up were compared. Only patients who had returned to work or those who had not done so only because they were "unfit for work" were included: patients who were unemployed for reasons unrelated to injury were excluded as were the retired, students and housewives. These data are summarised in table 9. No statistically significant association between claiming compensation and return to work was found at any follow-up using Fisher's exact test or the Chi-square test as appropriate ($p > 0{\cdot}05$).

5. *Post-concussional symptoms*

A substantial number of these severely injured patients experienced some post-concussional symptoms according to the reports both of the patients themselves and their relatives (tables 6 and 7). As a

Table 6 *Number of patients with "post-concussional" symptoms (headache, dizziness, irritability, poor concentration) as reported by relatives as a function of compensation claim.*

		Number of symptoms					*N*
		0	*1*	*2*	*3*	*4*	
3 months after injury	Claim	2	7	5	3	3	20
	No Claim	3	5	5	4	1	18
6 months after injury	Claim	3	5	6	4	2	20
	No Claim	4	5	4	6	1	20
12 months after injury	Claim	3	4	5	7	2	21
	No Claim	5	3	6	5	1	20

At each follow-up, comparison of claim and no claim groups by Mann-Whitney U test (2-tailed) reveals no significant difference. (p > 0·05)

Table 7 *Number of patients reporting "post-concussional" symptoms (poor concentration, dizziness, irritability) as a function of compensation claim*

		Number of symptoms				*N*
		0	*1*	*2*	*3*	
3 months after injury	Claim	5	4	5	3	17
	No Claim	10	7	1	0	18
p (Mann-Whitney U, 2-tailed) < 0·05						
6 months after injury	Claim	5	7	5	3	20
	No Claim	11	3	5	1	20
p (Mann-Whitney U, 2-tailed) > 0·05						
12 months after injury	Claim	3	8	8	2	21
	No Claim	9	7	5	0	21
p (Mann-Whitney U, 2-tailed) < 0·05						

Table 8 *Total number of symptoms (out of 20) reported by patients as a function of compensation claim*

	Time after injury		
	3 months	*6 months*	*12 months*
Claim	6·2	6·5	7·3
No Claim	4·2	3·8	4·5
Significance of:			
t test (2-tailed)	p < 0·05	p < 0·01	p < 0·01
ANCOVA with Age and PTA as covariates	p < 0·05	p < 0·05	p < 0·05

Table 9 *Return to work as a function of compensation claim*

		Working	*Not working*	*N*
3 months after injury	Claim	1	11	12
	No Claim	3	12	15
6 months after injury	Claim	3	11	14
	No Claim	6	8	14
12 months after injury	Claim	9	6	15
	No Claim	6	6	12

In each case, the Fisher exact test or the chi-square test, as appropriate, indicates no significant association (p > 0·05) between the variables.

Table 10 *Number of patients reporting post-concussional symptoms as a function of compensation claim (C = claim group, NC = no-claim group)*

	Time after injury					
	3 months		*6 months*		*12 months*	
	C	*NC*	*C*	*NC*	*C*	*NC*
Poor concentration	9/17	5/19	8/20	8/20	8/21	2/21
Depressed mood	11/18	8/18	12/20	7/20	11/21	9/21
Irritability	9/17	5/18	13/20*	5/20	15/21	9/21
Fatigue	11/16	7/18	14/20	10/20	15/21	9/21

*p (Chi-square) < 0·05.
For all other comparisons, p (Chi-square) > 0·05.

Table 11 *Number of patients suffering post-concussional symptoms according to relatives' reports as a function of compensation claim.*
(C = claim group, NC = no-claim group)

	Time after injury					
	3 months		*6 months*		*12 months*	
	C	*NC*	*C*	*NC*	*C*	*NC*
Poor concentration	11/21	6/20	10/20	7/21	10/21	5/20
Depressed mood	14/20	11/21	14/21	10/21	13/20	11/21
Irritability	12/21	13/21	16/21	13/21	15/21	13/21
Fatigue	18/20	15/20	12/20	16/21	15/21	11/21
Headaches	12/20	12/21	9/21	12/20	12/21	10/21

For all comparisons, p (Chi-square) > 0·05.

further way of examining the prevalence of post-concussional symptoms, the number of patients experiencing particular symptoms was calculated. The symptoms were a selection of those identified as "post-concussional" in the literature.[12 16 17] The patients' own accounts are summarised in table 10. Here, similarly to the analyses reported in table 7, there was a tendency for more claimants than non-claimants to report symptoms: all differences were in this direction although only one out of 12 comparisons reached the 5% level of significance on the Chi-square test. The relatives' reports of patients' symptoms are summarised in table 11. Here there were no significant between group differences, which is consistent with the analyses already carried out on relatives' reports. In addition to these symptoms, between one third and one half of the relatives reported that the patients showed intolerance of noise and reduced tolerance of alcohol, and most reported poor memory and increased anxiety. In short, relatives reported a wide range of post-concussional symptoms in both claimants and non-claimants.

Discussion

This study has found a high level of post-concussional symptoms in the severely head injured during the year following injury. This is in accord with the findings of Kelly,[20] who also found such symptoms following severe injury. It is at odds with the view of Miller that post-concussional symptoms are rare and are "hardly ever volunteered in the histories of patients (with) severe cerebral trauma".[17] However, failure to "volunteer" is not the same as absence: in the present study other symptoms and difficulties were more dramatic and evident but direct questioning uncovered post-concussional symptoms. These symptoms did not occur in all-or-none fashion but were present in varying numbers. This supports the view of Cartlidge and Shaw[16] that there is not a well-defined post-concussional syndrome but rather a loosely associated collection of symptoms. Moreover, the presence of post-concussional symptoms in the severely injured, especially those not claiming financial compensation, leaves open the possibility of an organic basis which would be much less likely if these symptoms were largely confined to mildly injured claimants, as has been alleged.[17]

There were some differences between claimants and non-claimants in the present study, and these should be considered in the context of the overall group comparisons. On psychometric tests, the tendency of claimants to obtain higher scores than non-claimants was attributable to the tendency for claimants to be younger. When age was controlled statistically there was no consistent difference between groups. In short, it seems that claimants did not attempt to fake low scores in order to present as more disabled than they were. Of course, this does not mean that no one ever tries to fake low scores. However, the present authors believe from their own clinical experience that serial testing uncovers this easily in the very few cases where it occurs, and the present findings support the view that faking low scores is rare.

The accounts of changes in the patients given by relatives in the course of separate interviews were not influenced by whether or not financial compensation was being claimed. The profiles of changes in claiming and non-claiming patients, obtained from relatives, were very similar indeed (fig) with no significant differences at any stage. Both groups reported the same overall picture as that reported in the larger group of 55 cases from which they were drawn:[10] emotional and subjective changes were considerably more common than other kinds of change. In addition, relatives' accounts of specific post-concussional symptoms in the patients did not differ between claimants and non-claimants. It seems, therefore, that relatives are good witnesses inasmuch as their accounts are not influenced by whether or not a claim for financial compensation is being made.

Unlike psychometric test scores and relatives' accounts, the patients' own accounts of their symptoms revealed consistent differences between claimants and non-claimants. Those who were claiming compensation tended to report more symptoms than those who were not claiming. While the differences may have been related to the differing age and severity of injury in the two groups, even when these two factors were statistically controlled, significant differences remained. Nor can it be argued that only those with poor outcomes considered it worth claiming: the key element in the decision to claim was culpability and the availability of witnesses.

The tendency for claimants to report more problems was slight *vis-à-vis* post concussional symptoms, reaching statistical significance in some analyses only (tables 7 and 10). However, this tendency became more robust when all 20 items in the symptom checklist were included (table 8) and appeared to be a general effect rather than one specific to particular symptoms. Nevertheless, the difference between groups was fairly modest in size and must be considered alongside our other findings. In particular, these patients did not fake low scores on psychometric tests and this study did not find evidence that claimants were absent from work for longer than non-claimants. Taken together, these findings do not support the conclusion that claimants make a widespread and concerted effort to present as more disabled than they are.

The findings of this study raise a number of issues. That different conclusions were reached on the basis of patients' and relatives' reports deserves comment. It has been noted that although agreement between patient and relative is usually quite high, relatives sometimes report changes in patients which the patients themselves fail to admit. This "lack of insight" seems to occur mainly over emotional and behavioural changes and is not generally a function of the patients' cognitive level.[6 29 30] Moreover, further evidence from our own research indicates that the personality of relatives may colour the accounts they give to a modest degree.[30]

Of more importance in the present context is the question of how we may account for the differences between the reports of patients who claimed compensation and those who did not. What factors underlie the deficits and symptoms observed after head injury? Firstly, it is beyond doubt that organic brain damage plays an important part both with regard to cognitive and other broader aspects of outcome.[5 31] It is also quite possible, as has already been argued, that post-concussional symptoms have an organic basis. Secondly, it is likely that a variety of psychological and social factors influence outcome: these may include premorbid personality and availability of social supports, although precise evidence about these remains lacking. In addition, Kelly[20] has argued that failure to be offered proper treatment may prolong post-concussional symptoms in claimants for compensation. Thirdly, there is no doubt that some patients malinger or simulate disability with a view to increasing a claim for financial compensation. Kelly argues that "The stupid, the greedy and the histrionic are always with us, but . . . it is unreasonable to suppose that (because some) attempt a fraud on insurance companies, all patients who have suffered a head injury for whom a claim is outstanding and who have . . . post-traumatic syndrome should therefore be labelled as fraudulent and refused treatment" (ref 20, p 24).

In the present study, it seems unlikely that organic factors could account for between group differences. There was no significant difference in PTA between groups, and in any event PTA was used as a covariate to control for the small difference which did exist. Nor were there differences in cognitive outcome which would have been expected if there were different levels of organic impairment. Malingering or simulation of disability also seem unlikely. Had this been present, one would have expected a greater difference between the reports of claimants and non-claimants together with some attempt to obtain low cognitive test scores. Relatives' accounts might also have differed between groups.

If neither organic factors nor malingering adequately account for the between group differences, can psychological factors do so? There is no reason to believe that there are systematic premorbid psychological differences between groups. However, Rutherford *et al* observed, in relation to mild injuries, that persisting symptoms may be related to blaming an employer or impersonal body for the injury, rather than oneself or another individual.[32] Merskey and Woodforde, again discussing mild injury, pointed out that the uncertainty which attaches to the process of litigation may be harmful.[19] And Kelly, as already noted, argued for an element of iatrogenesis.[20] It may be that such considerations best account for the differences between claimants and non-claimants observed in the present study.

Finally, two practical implications for assessing compensation claimants are drawn from the study. Firstly, it is important to assess cognitive function and to conduct separate interviews with relatives to obtain views unbiased by compensation. A careful interview with the patient is also required if all significant symptoms are to be uncovered: post-concussional symptoms are often present in the severely injured even if less obvious than their other problems. Secondly, examination should be made in the knowledge that major exaggeration of disability is rare.

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Methodological Problems in Assessing Psychosocial Recovery Following Severe Head Injury*

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ABSTRACT

A number of specific methodological issues have arisen in studies of the social, emotional, and behavioural sequelae of head injury. The accounts given by patients and relatives may differ: Patients may lack insight, and relatives – who are often under considerable stress – may themselves give distorted accounts. Moreover, the sequelae of head injury may not all be specific to brain injury but may include effects common to other forms of traumatic injury: The use of control groups may help disentangle specific and non-specific effects.

Damage to the brain resulting from severe head injury may result in major disability and in stress for both patients and their families (Brooks & Aughton, 1979; McKinlay, Brooks, Bond, Martinage, & Marsall, 1981; Oddy, Humphrey, & Uttley, 1978; Rosenbaum & Najenson, 1976). The purpose of the present paper is to consider some methodological issues which arise in assessing the social, emotional, and behavioural sequelae of injury and the effects of these on family and social life. Accurate assessment is needed both to increase our understanding of the effects of brain injury and to measure the changes in outcome effected by rehabilitation programmes.

Many of the general considerations in neuropsychological research discussed by Parsons and Prigatano (1978) also apply to research in this area. These will not be restated here except to note the importance of adequately describing samples in terms of demographic variables (e.g., age, sex, education, and socioeconomic level) and in terms of clinical indices. The subject of the present paper is a number of further methodological issues which have arisen specifically in studies of the social, emotional, and behavioural sequelae of head injury.

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Reports of psychosocial outcome have been based on a variety of sources of information. Some reports have been based on the patients' own accounts (e.g., Dikmen & Reitan, 1977), others have been based on relatives' views (e.g., McKinlay et al., 1981; Rosenbaum & Najenson, 1976; Weddell, Oddy, & Jenkins, 1980), and a considerable number on both patients' and relatives' views (Fahy, Irving, & Millac, 1967; Jennett, Snoek, Bond, & Brooks, 1981; Levin, Grossman, Rose, & Teasdale, 1979; Miller & Stern, 1965). Although it has been suggested that the accounts of patients and relatives may differ (Fahy et al., 1967), not all investigators have clearly differentiated their source of information (e.g., Jennett et al., 1981; Levin et al., 1979; Miller & Stern, 1965).

Discrepancies between patients' and relatives' accounts may be attributable to the cognitive deficits which often follow head injury (e.g., Brooks & Aughton, 1979; Schacter & Crovitz, 1976) leading to inaccurate accounts being given by patients. A lack of insight on the part of the patient, usually but not always over changes in character (Fahy et al., 1967; Miller & Stern, 1965; Thomsen, 1974), has been noted by some authors as a possible cause of the discrepancies although whether cognitive deficit or some other mechanism is responsible remains an open question.

These changes in character are associated with increased stress in caring relatives (Lezak, 1978; McKinlay et al., 1981; Oddy et al., 1978; Rosenbaum & Najenson, 1976), but little attention has been paid to the role of relatives' personality characteristics in determining how relatives cope with such stress. Indeed, it is not known whether personality influences their perception of the changes in the patient post injury. However, it is a reasonable hypothesis to suggest that relatives' personality does influence perception of change in the patient, so caution will be needed in suggesting simple and direct causal links between reported sequelae of injury and family disruption.

Caution in drawing causal connections is also required in attributing postinjury sequelae specifically to *brain* injury. Patients readjusting after other sorts of injuries may also have considerable psychological difficulty: For example, the anxiety and depression reported in White's (1982) study of patients with severe burns are also found in head-injured patients.

In view of these problems, the paper will discuss the following four major issues arising in research into the psychosocial outcome of severe head injury.

1. Do the accounts of patients and relatives differ and if so in what respects?
2. Do patients "lack insight" and is this the result of cognitive impairment?
3. What is the influence of relatives' personality on their reporting of changes in patients and stress on themselves?
4. How can control groups help us to identify the psychosocial sequelae which are unique to *brain* injury?

These questions will be considered on the basis of the present authors' research data and experience and in particular some examples will be drawn from a sample of 55 cases (46 male) aged between 16 and 60 years (mean 35.7) who had sustained severe blunt head injury. All had a posttraumatic amnesia (PTA) in excess of 2 days with a median of 21 days and they were drawn from a neurosurgical unit: Fuller clinical and demographic data were given in a previous publication (McKinlay et al., 1981). Both patients and relatives were interviewed at 3, 6, and 12 months postinjury in the course of a wider study, some reports of which have already been published (Brooks & Aughton, 1979; Brooks & McKinlay, 1983; McKinlay et al., 1981).

1. DO THE ACCOUNTS OF PATIENTS AND RELATIVES DIFFER AND IF SO IN WHAT RESPECTS?

Some reports of psychosocial outcome have been based on the patients' own accounts (e.g., Dikmen & Reitan, 1977), others on relatives' reports (e.g., McKinlay et al., 1981; Rosenbaum & Najenson, 1976; Weddell et al., 1980) and a considerable number on both patients' and relatives' views. As regards this last group, some investigators have clearly differentiated their source of information, reporting patients' and relatives' views separately (Oddy et al., 1978; Thomsen, 1974). Others have been less precise. Levin et al. (1979) used a structured interview with patients and "..... in most cases a separate interview with at least one family member" (p. 416). In the series reported by Jennett et al. (1981), a neurologist made a "clinical assessment of the degree of personality change from questioning of the patient and a close relative" (p. 289). Miller and Stern (1965) simply state that "a large amount of information was collected from relatives, medical attendants, lawyers and employers". This lack of precision may be important. Fahy et al. (1967) reported their impression that the accounts of patients and relatives may differ in particular respects.

> "Sensible of their difficulties in the fields of intellect, memory and speech, patients seldom acknowledge temperamental changes which in turn distress their family most" (p. 477).

The data collected by the present authors supports the view that there are systematic differences between patients' and relatives' accounts (Table 1). For brevity, only data for the 6 months postinjury assessment are reported, but the picture is very similar at 3 and 12 months follow-up in all relevant aspects. Agreement between patient and relatives is generally high as regards sensory and motor impairments. In the examples given, 77% agree as to whether or not the patient's sight is impaired (e.g., blurring, diplopia) and 85% agree on impairment of hearing. On questions about memory and concentration, there is an intermediate amount of agreement (65% and 63%). The least agreement is on emotional and behavioural changes. In the examples given, only 60% agree as to whether or not the patient has become more bad tempered and only 52% agree as to whether or not the patient has become more anxious.

Table 1

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

		Relatives' View	
		No	Yes
Patient's view	No		
	Yes		

Impaired Sight

25	9
3	15

$N = 52$

Impaired Hearing

43	5
3	2

$N = 53$

Impaired Memory

12	8
10	21

$N = 51$

Impaired Concentration

25	11
8	8

$N = 52$

Bad Temper

19	18
3	12

$N = 52$

Anxiety

15	21
4	12

$N = 52$

The data are based on 6 months post-injury assessment.
Positive responses indicate that the problem emerged/increased after injury and was still present between 3 and 6 months after injury.

These data are in accord with the observations of other researchers insofar as patients are particularly prone to failing to admit to emotional/behavioural changes which relatives report (Fahy et al., 1967; Thomsen, 1974) although in our sample levels of agreement were also far from high over cognitive changes such as memory and concentration. It does therefore seem to matter whether a patient or a relative is interviewed. Differences of view between them are not random. Particularly in the emotional/behavioural realm it is much more likely that the patient will deny a problem which the relative reports than vice versa. Possible reasons for this will be discussed in answering question 2 and 3 below. However, it is already clear from these data that precision about the source of information is important.

2. DO PATIENTS "LACK INSIGHT" AND IS THIS A RESULT OF COGNITIVE IMPAIRMENT?

One possible explanation for discrepancies between the reports of patients and relatives is that patients' accounts are inaccurate. Miller and Stern (1965) observed that some severely head-injured patients:

> "..... are euphoric and may make light of their disablement. Their insistence that all is well is a potential source of injustice unless either a percipient relative or an expert physician is able to show that disability is very much more serious than either subjective complaints or superficial observation of performance would suggest." (p. 225).

It may be that the cognitive deficits which follow severe head injury (e.g., Brooks & Aughton, 1979; Levin et al., 1979) lead to a general failure to perceive disabilities and deficits, especially in the most severely impaired patients.

Thomsen (1974) and Fahy et al. (1967) noted that patients with personality changes were often unaware of these. These authors seem to be suggesting a more circumscribed lack of insight which they do not attribute specifically to cognitive impairments.

As already noted, the present authors' data confirms that disagreement between patients and relatives is most likely to occur over changes in character, and that patients are much more likely to deny changes which relatives report than vice versa (Table 1). To assess the extent of disagreement between patient and relative, 18 items about which both patient and relative had been asked, were analysed. A count was made of the number of cases where the patient denied a change in himself/herself which had been reported by the relative as present in the patient. In the majority of cases it was found that disagreement between patient and relative was limited to between 0 and 3 items out of 18.

In order to assess whether the extent of such disagreement was related to the extent of cognitive impairment, a number of analyses was carried out. The extent of disagreement was correlated with scores on a number of psychometric tests (measures of verbal and nonverbal intelligence, verbal and visual recall, and verbal fluency and comprehension). There was no consistent pattern with only isolated correlations reaching the 5% significance level. These analyses were repeated using Verbal IQ as partial correlate in an attempt to partial out effects of premorbid intellectual level. Again there was no consistent pattern of significant correlation. In short, it seems that where patients deny problems which relatives report them to have (i.e., when patients "lack insight"), this is not related to cognitive deficit.

This failure to find a relationship between "lack of insight" and cognitive scores was confirmed by using *t* tests to compare cases in which the extent of disagreement was high with those where it was low (using an approximate median split). No consistent pattern of significant differences was found. When the extent of disagreement was calculated separately for physical, for memory, and cognitive, and for emotional, and behavioural items, and the procedure repeated, the same result was obtained. In short, no relationship was found between "lack of insight" in patients (i.e., number of items on which they denied a problem reported by the relative) and cognitive scores whether "lack of insight" was considered globally, or specifically in relation to these three types of items.

Finally, although this section has been concerned with lack of insight, not all "bias" need be attributable to patients being inaccurate. It is also possible that relatives' perceptions are coloured in a systematic way, and this will be considered next.

3. WHAT IS THE INFLUENCE OF RELATIVES' PERSONALITY ON THEIR REPORTING OF CHANGES IN THE PATIENT AND STRESS IN THEMSELVES?

It is precisely these changes in character which have been so prominent in the consideration of lack of insight in patients which have also been found to be associated with stress in relatives (Fahy et al., 1967; Lezak, 1978; McKinlay et al., 1981; Oddy et al., 1978; Rosenbaum & Najenson, 1976; Thomsen, 1974). Although it has been reported that parents have less difficulty in coping with head-injured offspring than spouses have with head-injured partners (Panting & Merry, 1972; Thomsen, 1974), little attention seems to have been paid to the personal characteristics which may enable a relative to cope with the very considerable stress involved. In particular, certain personality characteristics (e.g., emotional stability) may enable relatives to cope with stress more easily (Denney & Frisch, 1981). Moreover, it is quite conceivable that the relatives' personality will influence his/her perception of changes in the patient.

To investigate this possibility, an assessment of the personality of the relatives was made using a very brief (15 item) version of Eysenck's personality scale (Eysenck & Eysenck, 1975) providing measures of extroversion (E), neuroticism

(N), and psychoticism (P). Eysenck and Eysenck (1975) describe the three dimensions, which are conceptualised as continua, as follows:

The typical extrovert is gregarious, easygoing and impulsive while the typical introvert is reserved and cautious. The high neuroticism individual is anxious, depressed, overly emotional and inclined to over react: in short "a worrier". The other end of this dimension (stability) is characterised by calmness and even temperedness. High scorers on the psychoticism dimension tend to be solitary, insensitive and hostile.

Given the nature of these constructs and the established relationship of neuroticism with stress-related health problems (Denney & Frisch, 1981), it would be expected that N would be particularly related to high stress experienced by relatives. This was indeed the case. Relatives' N scores correlated significantly with the amount of stress (measured on a 7-point analogue scale) which they report experiencing: taking into account follow-ups 3, 6, and 12 months postinjury, correlations between N and perceived stress ranged between .43 and .50 ($p < .01$). No significant correlations were obtained between stress and relatives' P or E scores ($p > .05$). Moreover, P or E scores did not seem to influence relatives' reports of changes in the patient as significant correlations between P or E scores and relatives' reports about changes in the patients were lacking. However, when relatives' N scores were correlated with their own reports of post injury changes in the patient, consistently significant correlations emerged (Table 2). Relatives' N scores correlated most highly with their report of emotional/behavioural changes in the patients and showed lesser, if sometimes significant, correlations with their account of physical/cognitive changes.

It seems therefore that relatives' personality is related to the reports they give. It may be that higher N relatives make more of the patients' difficulties; or it may be

Table 2

Pearson Correlation between Relatives' "Neuroticism" Scores and Their Account of Patient Change.

		Relatives' Reports of Changes in Patients	
		Physical	Emotional
Relatives' *N* Scores at:	3 months	.17 NS	.35**
	6 months	.24*	.42**
	12 months	.18 NS	.39**

NS $p > .05$ * $p < .05$ ** $p < .01$

that their spouses also tend to be more "neurotic" and therefore to experience more difficulties. No direct test of this could be made as patients were not assessed on the Eysenck measure.

However, the extent of the influence of personality is not overwhelming. When partialling and covarying procedures are used to control for its influence, it remains the case that relatives report subjective/emotional changes in the patients more frequently than any others and that emotional/behavioural changes are most related to the stress experienced by relatives, findings which we have already reported (McKinlay et al., 1981).

The fact that personality does have an influence indicates the need for caution in drawing causal inferences. In a number of studies (McKinlay et al., 1981; Oddy et al., 1978; Rosenbaum & Najenson, 1976), relatives were asked to report changes in the patients subsequent to injury and also the degree of stress they themselves experienced. In two of these studies (Oddy et al., 1978; Rosenbaum and Najenson, 1976) the authors appear to assume that the reported changes in the patients are a cause, or else they state that they are a "source" of stress for the relatives. This may be so; but it may also be that relatives under stress take a more gloomy view and overestimate the effects of injury on the patient. In short, the causal relationships may not be simple (See Fig. 1) and attention needs to be paid to personality factors in assessing this aspect of psychosocial outcome.

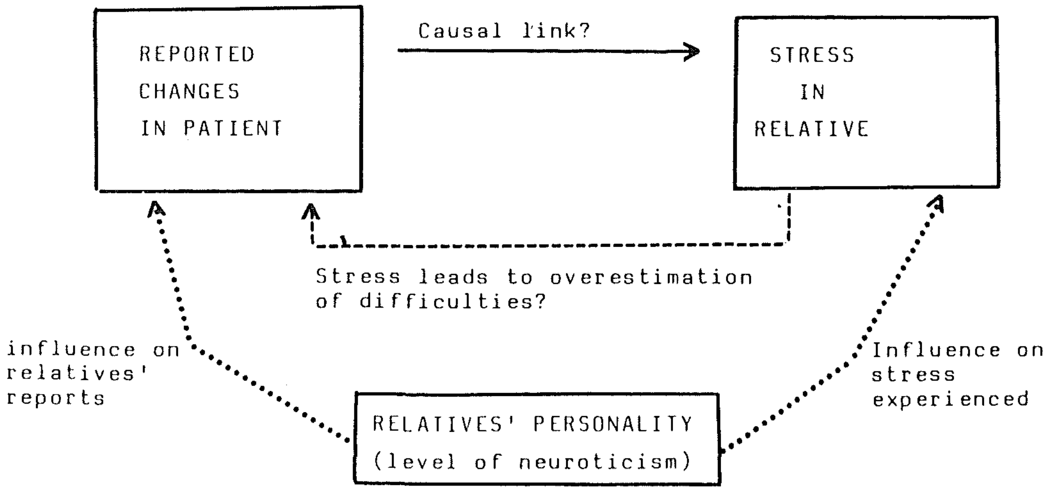

Fig. 1. Possible relationships between relatives' reports, stress in relatives, and personality.

4. HOW CAN CONTROL GROUPS HELP US IDENTIFY THOSE PSYCHOSOCIAL SEQUELAE WHICH ARE UNIQUE TO BRAIN INJURY?

The present authors have previously noted that on the basis of relatives' reports, some postinjury changes in the patient (especially emotional/behavioural problems) tend to become more frequent during the year after injury (McKinlay et al., 1981). Conversely, other problems (physical, self-care, language difficulties) become less frequent. Further examples of this are given in Table 3.

Table 3

Examples of Patients' Problems Which Change in Frequency over Time (Based on Relatives' Reports).

	Percent Reporting		
	3 months	6 months	12 months
Problems Increasing			
Mood changes	33	38	62
Bad temper	48	56	67
Social withdrawal	12	19	27
Problems Reducing			
Slowness	86	69	67
Needing constant supervision	26	17	11
Sight impaired	53	47	42

Why should this be? It may be that emotional/behavioural problems (e.g., bad temper, mood changes) are a direct result of brain injury, but while they are present from injury onwards, they are not observed or admitted, or else they are allowed for and thought unremarkable in the early stages of recovery. On the other hand, it may be that these problems are not a direct result of injury but represent adverse psychological reactions to disability and that they do, in fact, increase over time.

As regards the personality changes and impairments of concentration and memory which frequently follow severe injury, Miller and Stern (1965) have suggested that "the genuineness of such disablement is unquestionable" and that the deficit is of "organic nature". They also conclude that it is rare for severely injured patients to exaggerate their symptoms with a view to maximizing financial compensation, a view supported by our own research (McKinlay, 1982). However, others have taken the view that poor premorbid adjustment is an important contributor to outcome (e.g., Fahy et al., 1967), presumably for psychological rather than organic reasons. Moreover there is evidence that patients who have sustained other sorts of injuries have considerable psychological difficulties in readjustment. White's (1982) follow-up of severely burned patients is an example.

Indeed, it is difficult to believe that there is not some element of psychological reaction involved in adjusting to a diminution of personal skills or disability. However, control or comparison groups which might serve to clarify this issue have not generally been used despite the example set by Rosenbaum and Najenson (1976) who compared their sample of penetrating head injuries with paraplegics and normals.

Ideally a control group differs from the experimental group only with respect to the independent variable under study. With clinical populations the selection of control groups often proves very difficult. In order to determine which sequelae of severe head injury are distinctive, it is necessary to obtain a control group which is similar to the head-injured groups in certain respects, yet has no brain injury. The control group should firstly be drawn from a similar "at risk" population with the over-representation of the young, of males, and of the lower socio-economic classes which was found in the head-injured population (Field, 1976). Control subjects should also have sustained traumatic injury, life threatening in some cases, which leads to significant disability and the associated reevaluation of life plans (see Table 4). Patients with severe burns exemplify a group which meets some of these criteria. Such patients have sustained traumatic and possibly life-threatening injury from which a degree of disability is likely to result, including difficulty in psychological adjustment (White, 1982). However, they are not drawn from the same "at risk" population as the head-injured in at least some respects (e.g., age and sex distribution) although a proportion are said to have premorbid "social problems" (Cason, 1981). Similar strictures apply to a number of other groups: e.g., cardiac patients may suddenly become disabled but they are drawn from a different population in terms of age and other "at risk" characteristics (e.g., Russek & Russek, 1977) and are not traumatically injured.

Young orthopaedic patients with major fractures are drawn from a similar "at risk" population to the head-injured and have been used as control groups in studies of the cognitive sequelae of head injury (Brooks & Aughton, 1979). Another group drawn from a similar "at risk" population is the mildly head-

Table 4

Matching Parameters for an Appropriate Control Group for Studies of Psychosocial Outcome of Severe Head Injury.

(a) Drawn from similar "at risk" populations to ensure similar premorbid status.

(b) Have sustained traumatic injury leading to hospitalisation.

(c) Injury threatens life in a proportion of cases.

(d) Significant disability causes possibility of adverse psychological reaction.

injured. Both these groups have premorbid characteristics similar to the severely head-injured (i.e., average intellectual ability is lower, they tend to be of lower socio-economic class and to have poorer social and emotional adjustment than average). However, while such groups form useful controls for studies of cognitive recovery, they are less suitable for studies of psychosocial sequelae. This is because these groups are less severely injured and can be expected to make a more or less full recovery over a few months; adverse psychological reaction to disability would therefore be expected to be less marked and less prolonged.

Patients who come closer to meeting the requirements for appropriate controls are paraplegics. They have been used by other researchers (Rosenbaum & Najenson, 1976) as well as by the present authors. Such patients have sustained traumatic and possibly life-threatening injury which results in serious persisting disability. They tend to be young, with an over-representation of males, and, in the present author's sample at least, are similar in terms of other "at risk" characteristics. These considerations are summarized in Table 5.

Table 5

Advantages and Disadvantages of Possible Control Groups for Studies of Psychosocial Outcome of Severe Head Injury.

Control Group	Advantages	Disadvantages
Severe burns	Traumatic injury Significant disability	Different at risk population
Major limb fractures (Orthopaedic patients)	Traumatic injury Similar at risk population	Less disability
Paraplegics	Traumatic injury Similar at risk population Major disability	Better rehabilitation? Direct effects of spinal injury on emotional reactivity?

However, there are a number of between-group differences which pose problems. Paraplegics' disability is both severe and final, which may make adverse psychological reactions particularly acute. On the other hand, it may be argued that, since their disability is visible and public, it may be easier to adapt to and may carry less stigma than mental defect. Rehabilitation for paraplegics is generally well established with specialist units staffed by experienced personnel and this too is likely to make adjustment to disability a somewhat different process to that of the head-injured for whom specialist rehabilitation is less well established at the present time.

Finally, it has been suggested that spinal injury, particularly if the lesion is high, may have some direct effect on emotional reactions (Treischmann, 1980).

CONCLUSIONS

1. In studies in this area it is essential to make clear what is the source of information. The accounts given by patients and relatives not only differ but do so selectively with emotional/behavioural difficulties often alleged by relatives and denied by patients.
2. The extent to which patients deny difficulty which relatives report as being present in the patient was not found to be related to cognitive deficits.
3. The personality of informants influences the accounts they give both of certain changes in the patient and the amount of stress they themselves are under.
4. Possible sources of bias or colouration of data need to be borne in mind and caution exercised in postulating causal links.
5. The phenomena observed and reported following severe head injury will be a mixture of specific effects of brain injury and general effects due to reactions to injury, hospitalisation, threat to life and so on. The use of control groups is advocated to help disentangle direct effects of brain injury from adverse psychological reactions. Paraplegics would appear to form one promising if far from ideal control group in this respect and other comparisons will also be of value.

Research in the area of psychosocial outcome of severe head injury has hitherto been largely descriptive. However, as researchers seek to relate the nature and extent of brain damage to eventual outcome, or to draw connections between cognitive impairments and psychosocial outcome, or to map the effects of rehabilitation, the need for precision will increase. Real relationships may be attenuated or masked by unaccounted-for variance if researchers fail to make specific their source of information, ignore sources of bias and colouration including personality factors, and fail to differentiate the specific effects of *brain* injury from the more general effects of disability.

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