THE LONG-TERM IMPACT OF SEVERE HEAD INJURY ON THE FAMILY

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ABSTRACT

The purpose of this study was to examine the impact of brain injury upon the family of the brain-injured patient. Although some research into the psychosocial sequelae following head injury and the direct and indirect effects of severe head-injury upon the family have been conducted, these studies have largely been of a quantitative nature. For this reason, and with a view to expanding upon the existing findings, the present study was qualitative in nature in order to gain an indepth understanding of relatives' experience of living with and caring for a severely head-injured family member. In addition, ways in which family members coped with the impact of the brain injury were elicited.

Participants were caregivers to 11 severely head-injured patients who were representative of a range of socio-economic groupings and racial classifications. Severity of head injury was controlled for and participants were interviewed two or more years after the head injury had occurred. Demographic and injury related data were elicited by means of a questionnaire. Thereafter, data was collected by means of in-depth semi-structured interviews. A number of indices were developed based on a qualitative and descriptive analysis of the data.

The study found that the main source of distress experienced by caregivers related to emotional rather than physical symptomatology. All types of family relationships were profoundly affected by the patient's brain injury, although the caregiver's relationship with the patient appeared most vulnerable. Formal sources of support were considered inadequate and most caregivers relied heavily on emotional support, particularly from an intimate source. Coping responses were dependent upon coping resources available. Families of brain-injured patients who were racially and socio-economically disadvantaged were subjected to additional stress related to the unavailability of services and the randomness with which services that were available were dispensed. Rehabilitation services appeared to be failing to meet the needs of "brain-injured families" (Brooks, 1984) as they concentrated on the patient's physical handicap rather than emotional sequelae of the head injury.

Finally, suggestions were made for the institution of an appropriately designed multidisciplinary rehabilitation programme which would meet the needs of all brain-injured families.

CONTENTS

INTRODUCTION

Head injury is a relatively common cause of hospitalization and prolonged disability (Oddy, Humphrey & Uttley, 1978) and more often than not, it is the younger and more robust members of the community who are affected. Severe head injury causes brain damage leading to physical, cognitive and behavioural changes in the injured patient. The physical effects, ranging from sensori-motor disturbance to post-traumatic epilepsy, have been well researched (Jennett, Snoek, Bond & Brooks, 1981; Levin, Grafman & Eisenberg, 1987) as have the cognitive sequelae and deficits (Brooks, 1984; Levin et al. 1987). In recent years the previously underresearched area of "psychosocial" sequelae following head injury has been investigated. Such psychosocial consequences of brain injury include the behavioural, social and emotional as well as the cognitive changes in the patient together with the direct and indirect effects of the patient's injury on his/her family. It is this latter aspect which is the subject of the present study, the broad purpose being to investigate a range of issues concerning the stress relatives experience in relation to a head-injured family member. Furthermore, factors which exacerbate or ameliorate the stress experienced by the family as well as coping strategies employed by them will be examined. With a view to giving a context to this investigation, a brief review of the relevant literature concerning the effects of head injury on the family of the head-injured patient follows, together with aspects concerning rehabilitation. In addition, conceptual issues with regard to stress, coping and social support and their relevance to brain-injury are discussed.

Head Injury and the Family : A brief review of the literature

As early as 1967 Fahy, Irving and Millac, while reporting on a six year follow-up of 32 very severely brain-injured patients, observed that whereas patients denied or lightly dismissed any disabilities, relatives reported differently. Although reports of difficulties in intellect, memory and speech were made, relatives appeared to be much more disturbed by marked changes in the temperament of the patient. Thomsen (1974), Panting and Merry (1972), Bond (1975) and Cartlidge and Shaw (1981) have all indicated that mental and personality changes carry more stress for the family than physical disabilities. In this connection, Jennett et al. (1981) state that "previously quiet and kind (brain-injured patients) may now be talkative and tactless, liable to outbursts of temper, forgetful and irritable. This is much harder for relatives to bear than hemiplegia or even paraplegia" (p.293).

Panting & Merry (1972) in a study of 31 patients admitted to a rehabilitation centre, found that whereas there was a marked tendency for physical deficits to recover, emotional disturbance did not improve and was far more difficult for relatives to deal with.~Almost two-thirds of the relatives needed treatment with tranquillizing medication or sleeping tablets due to stress experienced in the family as a result of the presence of the brain-injured patient. Of particular distress to relatives were the patients' outbursts of rage. Thomsen (1974) supported previous findings that neuropsychological sequelae (particularly memory impairment) were troublesome, but of much greater concern to relatives were "changes in personality (which) created the greatest trouble in their daily living" (p.181). Pathological laughter was of particular concern to relatives.

Relatives in both the Thomsen (1974) and Panting & Merry (1972) studies were unanimous in complaining of poor communication with medical professionals and inadequate services. Thomsen found that working-class relatives particularly complained of lack of information, and felt this was largely due to these relatives failing to understand or to remember what the doctor had said. Romano (1974) found a marked tendency for relatives to deny disability and to imagine measurable improvement to have occurred when in fact it had not. Unfortunately, Romano does not give details of the duration of this tendency to denial.

Both Thomsen (1974) and Panting and Merry (1972) found that marital relationships tended to be less stable under stress than parent-child relationships. Rosenbaum and Najenson (1976) compared the wives of 10 men with penetrating missile wounds of the brain with the wives of 10 paraplegics and 10 normal controls. They found that the wives of the brain-injured patients had a more restricted social life and were significantly more depressed than the wives of the paraplegics. Brain-injured husbands were much more likely to be described as self-orientated and dependent. In addition, although sexual functioning had decreased in both groups, the reason underlying the decrease was different : in the paraglegic group it was due to spinal physical difficulties, whereas for wives of brain-injured husbands it was due to interpersonal distress in that they felt distaste at having sexual contact with someone whom they saw as a changed person. It was also found that role changes within the family contributed significantly to depression in the wives of the brain-injured group.

Oddy et al. (1978), using a depression inventory administered to the relatives of severely head injured patients within a month of the injury and again six and twelve months later, found relatives of those patients who had had a post-traumatic amnesia of more than 7 days to be under significant stress. Depression in relatives appeared to be related to their perception of personality changes and subjective defects in patients rather than whether or not the patient had resumed work and leisure activities. Of particular distress were the patient's "verbal expansiveness" (talking too long, too loud and with too little regard for logical continuity) and "confusion" (referring to a tendency towards forgetfulness and disorientation). In a two-year follow-up, Oddy and Humphrey (1980) reported, in the case of the more severely head-injured patients, that there were marked impairments reaching family crisis point in some cases.

McKinlay, Brooks, Bond, Martinage & Marshall (1981) attempted to identify the objective and subjective "burdens" that traumatic brain damage imposes on the patient's family at intervals in the first year after injury. By using a 90 item structured interview schedule, a close relative of the patient supplied information regarding the patient's physical and mental conditions, behaviour and self care (objective burden). The problems most frequently reported were emotional disturbances (particularly impatience and irritability), poor memory, and subjective symptoms (slowness, tiredness), with physical disability being reported far less commonly. The subjective burden was measured by a 7-point scale on which the relative rated the degree of distress experienced due to changes in the patient since injury. It was found that 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. In addition, changes in personality, marked by aggression, irresponsibility, childishness and inconsiderate behaviour produced significant burdens upon the relatives. Brooks & McKinlay (1983) also examined the relationship between strain in relatives and personality change in the patient in more detail, using bipolar adjective checklists. As the year after the injury progressed, an increased association developed between personality change in patients and subjective burden in the relatives. Features of personality change associated with "high burden" in relatives included reduced control of emotion (quick temper, irritable, changeable), reduction in energy (lifeless, listless), immaturity, emotional coldness, unhappiness, cruelty, meanness and unreasonableness. Brooks, Campsie, Symington, Beattie & McKinlay (1986) further assessed relatives' stress five years post-injury in a similar manner to that described in the 1981 paper and found that relatives were under significantly more strain than at 1 year. The best predictor of strain in the relative was the magnitude of behavioural and personality change in the patient.

Prigatano (1985) substantiates this opinion by stating that it is the paranoid, depressed and belligerent brain-injured patients who cause by far the most stress for family members because they are unable to cope with the inevitable breakdown in interpersonal relationships between family members.

Lezak (1978) reported on problems related by families of brain-injured patients who formed part of an open-ended drop-in discussion group provided for their support. Feeling trapped and isolated were two common complaints. In addition, families were often abandoned by the extended family or alternatively, relatives were inclined to be critical of the person caring for the brain-injured patient. Physical abuse by the patient was also a common problem.

Overprotection of the brain-injured patient was seen as a major problem, encouraging dependency, feelings of worthlessness and a "childish negativism". Spouses of brain-injured patients expressed feelings of guilt and fear of social condemnation should they desire a divorce.

Psychiatric Aspects of Head Injury in the Patient

The psychiatric aspects of head injury refer to the personality and behavioural disturbances that typically follow craniocerebral trauma (Prigatano, 1987). As revealed in the above review of the literature, it is these disturbances which cause relatives of brain-injured patients the greatest distress. Lezak (1978) outlines the "characterological alterations" in persons with adult-onset brain injury which are most likely to create adjustment problems for their families. These are :

1. <u>An impaired capacity for social perceptiveness</u> where former powers of self-criticism and self-reflective behaviour are diminished or lost with associated development of egocentricity and loss of empathy.
2. <u>Impaired capacity for control and self-regulation</u> giving rise to impulsivity, impatience and restlessness.
3. <u>Stimulus-bound behaviour</u> presenting as a loss of ability to initiate and plan activities for daily living resulting in social dependency.
4. <u>Emotional alterations</u> which include apathy, irritability, lability, silliness and either a greatly increased or virtual loss of sexual drive.
5. <u>Inability to learn or profit from social experience</u> even when the ability to absorb new information may be intact, leading to conceptual and behavioural rigidity which, in turn, leads to difficulties of the type in 2 and 3 above.

These deficits, taken together with the two basic cognitive handicaps which affect almost all brain-injured patients, i.e. a decrease in mental agility and memory impairment, cause considerable stress for family members. Awareness of these disabilities as well as possible physical and language difficulties, leads to anxiety in the patient, often resulting in depression and increases in irritability and impatience with lowered tolerance for frustration and outbursts of temper (Bond, 1984; Prigatano, 1987). In this connection, Lishman (1973) points out that changes of temperament in the brain-injured patient often represent an intensification of premorbid personality traits. In addition, extreme suspiciousness and even paranoid delusions may develop. Bond (1984) points out that these forms of "primary disability" are established as early as 6 to 9 months after injury in adults, and although modifications take place over many months, influenced in large part by pre-morbid characteristics, for the most part improvements represent patients' adaptation to their primary deficits and development of techniques for overcoming, in part, lost abilities.

Rehabilitation after head injury

Rehabilitation assists the process of recovery after head trauma with a view to restoring physical, mental and social capabilities (Bond & Brooks, 1976). Evidence to date suggests that therapeutic treatment is most effective if it is initiated at the earliest opportunity during the first six months after injury (Bond & Brooks, 1976). Thomsen (1974) points to the importance of counselling the family during the early phase of recovery to prepare it for possible changes in the patient's behaviour which serves the purpose of averting inappropriate reactions that complicate rehabilitative efforts.

There is general consensus in the literature on rehabilitation of the severely head injured that too much emphasis is placed on physical handicap while social handicap is often neglected (London, 1967; Bond & Brooks, 1976; Brooks, 1984; Fugel-Meyer & Fugel-Meyer, 1988) and that generally there is a failure to appreciate the severe family disruption which can result from one of its members sustaining severe brain damage (Jennett, 1975). In this connection, Brooks (1984) observes that :

> rehabilitation services which concentrate solely on physical handicap in the patient are failing to meet the needs of the patient and his family, and rehabilitation services must now consider adopting the concept of 'the head-injured family' rather than solely the head-injured patient. (p.144)

It would thus seem that more often than not the needs of families are not being met, a fact borne out by the dissatisfaction expressed by relatives when questioned about the facilities available and the information given to them (Romano, 1974; Thomsen, 1974; Oddy et al. 1978). Fugl-Meyer and Fugl-Meyer (1988) observe that the patient as well as the family are in a state of psycholgical crisis in the early stages after head trauma and if not given adequate empathy and information, may resort to permanently maladaptive defense mechanisms. They emphasize that "even if the patient cannot cooperate at all or only to a very limited degree, those close to him may need and appreciate supportive therapy" (p.53).

An exception to the above rule is a rehabilitation unit in Israel (Najenson, Mendelson, Schechter, David, Mintz & Groswasser, 1974; Rosenbaum, Lipsitz, Abraham & Majenson, 1978) where patients have access not only to physiotherapy and other rehabilitation therapies, but also to intensive psychotherapy, behaviour modification programmes and psychiatric advice. In addition, family members are seen in group therapy in an effort to facilitate understanding and acceptance of the patient's disabilities and alterations in personality. The goals of family therapy include discussing realistic expectations regarding the patient's behaviour, and discouraging over-protective behaviour by assisting family members in examining their guilt feelings. In this regard, Tollman (1988) explains that "family counselling is essential, being educative, focusing upon the behavioural consequences of the injury, and developing strategies to deal with them. If personal difficulties in the support system are revealed in the course of counselling, psychotherapy should be recommended." (p.24).

The Concept of Stress and its relationship to brain-injury

A plethora of meanings abound in the literature on the concept of stress. In this study, stress is defined relationally by reference to both the person and the environment, where there is an imbalance between the demands of the environment and the individual's ability to respond adequately to these demands (Holroyd & Lazarus, 1982). This definition contrasts with those where stress is either conceived of as a stimulus, i.e. a condition that produces disturbance or some sort of reactive change, or as a response, describing the nature of the disturbance itself. An example of a stimulus would be a negative life event (Holmes & Rahe, 1967) while examples of responses include physiological reactions (Selye, 1967), cognitive disruption or behavioural disorganization (Holroyd & Lazarus, 1982). Now, it may be postulated that a brain-injury constitutes a stimulus or stressor which could be regarded as a negative life event. However, it is argued that a stressful event (such as head-injury) does not impinge upon passive individuals, as is implicitly assumed by stimulus definitions of stress, but rather upon individuals who are imbuing the stressful event with personal meaning and struggling to control and muster such an event (Holroyd & Lazarus, 1982). The appraisal of each stressor will thus depend upon a number of factors, including attitudes towards the stressor, prior experience with it, knowledge of its consequences and evaluation of its apparent costs (Lazarus, 1966). Thus a stressful life event such as the death of a spouse may be traumatic for one woman and a relief for another or may cause extreme financial difficulties for a working class wife as opposed to a middle class wife who has been financially provided for. Similarly, head injury as a stressful life event will, it is postulated, impinge differently upon the main care-giver of the head-injured family member than it would upon other family members, and differently upon families with and those without the financial means to cope with the trauma and its repercussions.

More recent research on life event studies has placed greater emphasis on the quality of the events rather than solely on the magnitude of the changes they entail when discussing the stressful impact of such events (Pearlin, 1982). The desirability of the event and its voluntary or involuntary character are qualities considered. Another is whether the event is scheduled to happen (such as marriage, having children) or unscheduled (as in job disruption, premature death, injury and illness). In contrast to events that are scheduled, and which are preceded by a great deal of anticipatory coping, unscheduled events, which descend upon individuals without prior warning, are notably associated with stress (Pearlin, 1982).

A second major type of stressful experience is that which is repeated or chronic (Kessler, Price & Wortman, 1985; Pearlin, 1982). In recent research some investigators have emphasized that in most cases life events bring about chronic stressors (Pearlin, Lieberman, Menaghan & Mullan, 1981; Thoits, 1982). By way of example, loss of a spouse may force a widow to contend with a variety of daily stressors such as relocation, financial problems, and single parenting.

It the light of the above discussion, it is postulated that brain-injury constitutes an undesired, unscheduled event in a family, arousing stress directly and indirectly by changing adversely the conditions of life for the family affected. In addition the presence of a severely brain-injured person imposes a repeated or chronic strain on family members and more particularly on the person who is most concerned with the daily care of the patient. However, Young's (1980) caution that "stress" should not be decontextualised from the wider historical context is of importance. Thus, head injury due to violent assault in the Black townships of South Africa cannot be compartmentalized into the same "stressful life event" as that occasioned by a head injury arising from an inter-varsity rugby match. In this connection, Turton (1986) identifies states of health, personal histories, social, economic and political conditions and interpersonal relationships as some of the factors that produce and modify the occurrence of stressful experiences.

The Concept of Coping

The coping process, like stress, is multifaceted and a single conceptual definition is problematic. Broadly speaking, "coping" refers to efforts to manage environmental and internal demands and conflicts among them (Lazarus, 1966; Holroyd & Lazarus, 1982), such efforts to manage referring to a dynamic constellation of thoughts and acts that constitute the coping process.

Shapiro (1983), in her review of family reactions and coping strategies in response to the physically ill or handicapped child, makes the important distinction between coping resources and responses. A coping response "is an action, thought, verbalization or feeling elicited by the stressor of illness, thus having a direct and identifiable link to this particular stressor" (p.915). Coping resources, on the other hand, refer to "aspects of the individual's external and/or internal environment which are either not directly or completely under the individual's control; they exist in a quiescent state, ready to mediate in a positive or negative direction the individual's response to the advent of a stressor" (p.915). Examples of coping resources in the "internal environment" include personality attributes such as self-concept and psychological resilience, and previous experience with other stressful situations. Aspects of the "external environment" include disease-specific factors (diagnosis and prognosis) and demographic and socioeconomic variables (social class, marital status, educational attainment, financial status, religious affiliation) and formal and informal support systems.

The conceptual framework reviewed by Shapiro has been expounded upon in some depth. It is felt that her view of the nature and type of coping responses generated by an individual being determined to some extent by the coping resources available is germane to this study of the coping strategies employed by families of brain-injured patients.

With regard to coping responses, Folkman & Lazarus (1980) have identified two general coping strategies : problem-focused and emotion-focused coping. Coping strategies which focus on the problem attempt to deal directly with the source of stress and include making alternative plans, seeking advice from others, taking specific action to deal with the situation, learning new skills directed at the problem and negotiating and compromising to try to resolve the issue. . However, if the problem is perceived as intractable, then it is more likely that emotion-focused coping strategies will be employed (Heller, Price, Reinharz, Riger & Wandersman, 1984). These strategies could involve direct efforts to control the emotion aroused by the problem by consciously postponing paying attention to the stressor, experiencing and working through one's feelings, maintaining a sense of pride and keeping a stiff upper lip, and tolerating ambiguity by withholding immediate action. However, emotion-focused coping may also involve resigned acceptance of the problem if it is decided that nothing can be done about it as well as emotional discharge such as verbal expressions to "let off steam", crying, smoking, overeating and engaging in impulsive acting out (Moos & Billings, 1982). In extreme situations, such palliative coping responses (i.e. managing of emotional responses) may represent the most appropriate, and often, the only means of coping, particularly where people of limited means have fewer options available to them. Finally, in addition to the two modes of coping discussed, Moos & Billings (1982) add a third coping strategy, that of appraisal-focused coping, involving attempts to define the meaning of the situation, and once the reality of the situation is accepted, attempting to redefine the problems with such strategies as reminding oneself that things could be worse or looking for positive aspects of the situation. Alternatively, such strategies as denying fear or anxiety under stress and refusing to believe the problem really exists are employed. In this manner, the way the problem is viewed is altered.

The concept of family coping (Shapiro, 1983) is one which has relevance for a study of the impact of brain-injury on the family. Shapiro delineates the goals of family coping strategies in response to major illness as follows : (1)Responding to the challenge of adaptation; (2)Maintaining a sense of membership in the family; (3)Reorganizing the family and reassigning roles; (4)Re-establishing an emotional baseline, and the mastery of resentful, self-accusatory and other negative feelings.

Social supports as stress buffers

There has been a growing interest in recent years in the role of social support in mitigating, or protecting a person from, the deleterious effects of stressful life events (Thoits, 1982; Kessler et al. 1985) and that a lack of such intimate relationships increases the adverse effects of stressors (Rutter, 1981). However, the concept 'social support', too, is multifaceted and an adequate single definition to provide a framework for research and clinical intervention has proved problematic (Leavy, 1983).

House (1981) has managed to integrate the many conceptualisations of social support and identifies four types of support behaviours : (1)emotional support which involves caring, trust and empathy; (2)instrumental support which includes helping others do their work, lending money and providing other direct assistance; (3)informational support involving giving information or teaching a skill which can provide a solution to a problem; and (4)appraisal support which involves providing information which assists an evaluation of personal performance. These four aspects are interrelated to form the complex concept social support. Clearly, the frequency of social contact and its availability have a bearing on whether such support provides a buffer against stress.

Social support can furthermore be divided into formal and informal sources of support (Lieberman, 1982). Brain-injury necessitates that there will be an increased contact with "formal" sources of social support (i.e. medical professionals and social services) whereas research has shown that families of brain-injured patients often suffer a reduction in the informal sources of social supports due to social isolation (Lezak, 1978; Brooks, 1984). The role played by other sources of informal support, i.e. kith and kin, also has implications for research on the effects of brain-injury on the family.

Although the hypothesis that support buffers the effects of stress (Cobb, 1976) is not regarded in the literature as conclusive (Kessler et al. 1985; Leavy, 1983), many studies indicate that certain types of support, particularly emotional support, have an important influence on the effects of stressful events. In addition, community attachments offer a specialized source of support, particularly for individuals whose identities are closely linked to ethnic origins (Lin, Simeone, Ensel & Kuo, 1979). Furthermore, the individual's perception of the quality of the support has relevance, i.e. how good it is rather than how much there is (Leavy, 1983). In this connection Kessler et al. (1985) caution against contamination of self-report measures of stress in that people who are experiencing distress may also judge their social relationships more negatively. In addition the subjective interpretation of social isolation is also related to psychological stress and distress (Noh & Turner, 1987).

Rationale for and aims of the present study

As is evidenced by the review of the literature, some inroads have been made into the previously underresearched area of the direct and indirect effects of brain-injury on the family. However, these studies have in the main been of a quantitative nature, making use of structured interview schedules or questionnaires to collect data relating to the presence/absence of changes in the patient from relatives and thereafter rating the relatives' psychosocial functioning by means of a standardized rating scale. Although these studies provide some replicable assessment of the functioning of a relative of a brain-injured family member, essentially they assess only one aspect of relatives' psychosocial functioning using either a mood rating or a stress rating. It is thus with a view to expanding upon the existing findings that the nature of the ensuing study is qualitative, the aim being to obtain from relatives, in their own words, descriptions of their experience of living with, and caring for, a severely brain-injured family member. Although interviewing as a research method may be subject to interviewer bias and may have suspect validity and reliability, it is argued that interviews provide the main means of access to the participant's subjective experiences not allowed for by more objective methods of research. Ashworth, Giorgi & de Koning (1986) point out that :

> The aim is to obtain rich and detailed descriptions of the respondent's own concerns, opinions and actions in her own words, rather than eliciting bits of behavioural responses to precategorized stimuli. One is more interested in how matters appear to the respondent than in how to fit answers into prefigured categories - the first step being uncensored, concrete descriptions which come prior to any efforts to control, manipulate or quantify what is said. (pp.338-339).

A further aim of this research is to elicit the coping strategies employed by relatives of severely brain-injured patients to master, tolerate or reduce the stress created by the presence of the brain-injured patient in the family. This is an area which has heretofore been underresearched and one which, it is argued, has practical implications for therapeutic intervention in brain-injured families.

METHODOLOGY

Subjects

The subjects in this study were 11 relatives of severely brain-injured patients selected from the records of the neurosurgery department of a large teaching hospital in Cape Town and from the membership list of a local Cape Town organisation providing support for the brain-injured and their families. All the patients experienced a post-traumatic amnesia (PTA) of greater than 48 hours (defined as the time elapsed between injury and the regaining of continuous day-to-day memory) assessed retrospectively, by careful clinical questioning, and/or the presence of coma assessed by means of a Glasgow Coma Score (GCS) (Teasdale & Jennett, 1974) of less than 8 recorded on admission to hospital and continuing for at least 24 hours (cf. Prigatano & Fordyce, 1985). In addition to controlling for the severity of head injury, the time which has elapsed since the head injury was restricted to a minimum period of 2 years. It is around this period that relatives become aware that prospects for further improvement in the social adjustment of the patient are for the most part limited (Oddy, Coughlan, Tyerman & Jenkins, 1985) and they now have to come to terms with the reality of the patient's disabilities and the problems facing the family. Pertinent biographical and injury related data concerning the 11 patients constituting this study are provided in Table 1. None of the patients constituting the sample had been able to return to work.

TABLE 1
Biographical and injury related data concerning headinjured patients

Age (years): Mean = 30,8 Range = 19-52
Sex : 10 Male 1 Female
Marital Status : 4 married; 1 divorced; 1 widow; 5 single
Post-traumatic Amnesia : Range = 14 - 120 days

14-29 days	30-39 days	>80 days
(2)	(1)	(8)

Cause of Head-Injury : Motor vehicle Accident : Pedestrian = 1
Passenger = 3
Driver = 3
Assault : 3
Industrial : 1

Each of the interviewees was the relative who bore the major day-to-day responsibility for the care of the patient ("the caregiver"). In every case, this was a woman. The subjects constituted a range of race groups classified according to the Population Registration Act, 1950, drawn from a cross-section of socio-economic levels, coded according to the main breadwinner's occupational status into two socio-economic status (SES) groups (Schlemmer & Stopforth, 1979), i.e. a higher SES group and a lower SES group, thereby making a comparison of these two groups possible where applicable. A comparison was regarded as necessary on the hypothesis that socio-economic status would have an impact on the problems facing the family of the brain-injured patient. Bearing in mind that socio-economic grouping and race classification tend to be conflated in the South African context, it was felt that race classification was an additional factor influencing the stress experienced by the family in relation to the brain-injury. Details of the socio-economic status and race classification of the families in this study are provided in Table 2.

TABLE 2
Details of Socio-economic Status of Families*

	No of Caregivers	Race Classification
HIGHER SES GROUPS:		
Professional & Managerial	2	White
Middle White-collar	2	White
Manual Foreman, Skilled Artisans Farmers & Status equivalent	2	Coloured
LOWER SES GROUPS:		
Routine Non-Manual & Semi-skilled Manual	2	Coloured
Unskilled Manual & Menial	3	Coloured (1) Black (2)

* Coded according to Schlemmer & Stopforth, 1979

Relationships of the caregiver to the patient included 4 wife-husband relationships, 6 mother-son relationships (including a case where the patient's wife had divorced him) and 1 sister-sister relationship. The average age of the caregivers interviewed was 45,7 years while the brain-injured patients being cared from by them ranged from 19 years to 52 years.

Apparatus

Two methods of data collection were employed: a questionnaire and an in-depth semi-structured interview. The questionnaire elicited demographic data and details of the injury (see Appendix I). The in-depth semi-structured interview was conducted according to a schedule covering the following broad areas of inquiry :

1. The daily routine involved in caring for the brain-injured patient.

2. Problems experienced by the family due to the brain-injury in the areas of changes in family routine, housing conditions and social and leisure activities, and financial implications and problems in family relationships.

3. Problems experienced by the family due to changes in the brain-injured patient.

4. Quality of contact with medical professionals and availability of social services.

5. The caregivers' perception of stress in relation to the brain-injured patient as manifested in themselves and in other family members.

6. Coping mechanisms employed by the caregiver and family.

7. Information which hindsight has provided for the relative concerned and how this could be useful to others in a similar situation.

This framework guided the course of the interview, but within each of the above categories flexibility was exercised, the interviewee being encouraged to share with the researcher exactly how she and her family have experienced the impact of the patient's brain-injury.

Procedure

All interviews were conducted in the interviewee's home and the participants were reassured of confidentiality. Two pilot interviews were conducted in order to ensure that the interview schedule was effective in obtaining the highly emotionally charged material to be tapped in this research.

In all, eleven interviews were conducted by the researcher. Prior to commencement of the interview, the aims of the research were explained to the interviewee. Thereafter the questionnaire was completed. Each in-depth interview lasted from 2 to 3 hours. All interviews were, with the permission of the participants, audiotaped and later transcribed. Due to the sensitive nature of the data collected, great care had to be taken in its elicitation. In this connection, the researcher found it necessary to provide counselling of the interviewee during the course of almost all the interviews conducted. No interpretation or confrontation of behaviour was attempted, the emphasis being on providing support and discussion of feelings and concerns.

Once the interviewing process had been completed, information was sought informally from occupational therapists, physiotherapists and social workers with regard to management of head-injured patients following discharge from hospital.

Analysis of Data

Data collected in the course of each interview were loosely content analysed. In this way certain themes and trends became apparent. The interview schedule provided the predetermined categories being investigated and, from each of these predetermined categories, a number of emergent categories were formulated. A qualitative and descriptive analysis of all responses was conducted by the researcher. As the number of participants was not sufficiently large to make it necessary to record the frequency of responses under each category, this procedure was dispensed with. However, adjectives such as <u>one</u>, <u>a few/some</u>, <u>most of/the majority of</u> or <u>all of</u> the participants will be employed to give some indication of the frequency with which a particular response was given.

The findings are presented as a systematic descriptive account of data collected in the interviews. Five foci have been isolated (based on the interview schedule) as follows :

1. Identification of problems related to the brain injury impacting upon the family household and upon family relationships.

2. Identification of problems related to characteristics of and changes in the brain-injured patient.

3. Availability and quality of social services and contact with medical professionals.

4. Relative's subjective perceptions of stress manifested in the family resulting from the patient's brain-injury.

5. Coping mechanisms employed by relatives to cope with the impact of the brain-injury.

Although the findings have been grouped together under these theme categories, it should be noted that issues discussed in one theme category often have relevance and implications for other issues in separate categories. When all the problems discussed separately are taken together, they collectively present the global impact of brain-injury upon family functioning.

FINDINGS

1. EFFECT OF BRAIN INJURY ON THE HOUSEHOLD

1.1 Changes in housing conditions

A few families were forced to change from double to single-storied accommodation in order to accommodate the patient's wheel-chair. For one family this change meant moving from a "coloured" area of Woodstock to a "white" area resulting in loss of social support for the caregiver :

> I haven't got friends here whereas when I stayed in the coloured part, where the coloured people are .... well, they care for each other, they're more supportive. The people here are much more for themselves ... I can't go out and say "Hey look man, I haven't got this, quickly lend me some" ... Here you must just stay inside and keep to yourself.
>
> I felt more free there ... to call somebody over the wall ... or just talk to somebody ... just to say hello and have a bit of contact. There you don't have to keep things in to yourself, you speak out, because in the coloured community most of the people have problems and you talk it out and you feel much better, whereas here you can't really talk to people in that way ..

Changes in accommodation also resulted in other family members losing friends from the previous neighbourhood.

Other alterations involved placing rails in bathrooms, alongside stairs leading to the house, above the patient's bed and changing doors to the sliding variety. None of the families in the lower SES groups had made alterations to their homes.

1.2 Financial implications

The greatest financial burden appeared to exist in the lower SES group where the brain-injured person had been the breadwinner. Initially wives were forced to give up employment to care for the patient, creating a severe financial burden for the family, and thereafter they had to seek work to support the family, often leaving their brain-injured husband to care for small children at home. These families experienced a severe financial burden as can be seen from the following comments :

> I get food (breakfast and lunch) at my work but I don't eat it - I save the bread and cheese to give to my children.
>
> We have been affected badly because ____ used to earn well. Now it is only me who works and I have to be very careful and not waste money. I must pay all the debts and I worry some times because in the middle of the month I have'nt got food for my children.
>
> Before my children stayed here with us in the hostel, now they stay with my mother (in Transkei) because I haven't got food and a lot of money to pay for the school.
>
> If only I could get more work I would be happy. I have only two char jobs a week and at one in Bishop Lavis I only get paid R12 a day. It costs me R1,80 in bus fare to get there but I must because we have no money.

Although the situation was less stressful where the breadwinner was a father and the brain-injured patient a child, these families worried about the future. One caregiver confided that while her husband worked "we're O.K, ... but he's due to go on retirement soon. We had hoped by this time that all our children would be off our hands and supporting themselves."

In a few of the families interviewed (in the higher SES groups) the mother had gone to work to supplement the family income and had used a proportion of her salary to pay a maid to stay with and care for the brain-injured patient.

The majority of families were claiming disability grants or Workmens Compensation grants in respect of the brain-injured patient. These appeared to vary a great deal according to the race group of the patient. One black patient who had been receiving R96 per month as workmens compensation for 3 years post injury had only recently found out, due to a chance remark by a friend in a similar situation, that he should in fact be receiving considerably more. After eliciting the assistance of a social worker, he has now managed to secure R200 per month. Another black patient, although assessed medically as qualifying for a disability grant, had still not received it two and a half years after the head injury. A social worker questioned by the researcher remarked that the Department of Co-operation and Development (governing Black disability grants) "is in a mess" and that "often applications for disability grants for black people are lost". It is thus incumbent upon these families to reapply once they have established that the application is lost. In a situation which was in stark contrast to these difficulties, a white patient who was injured while returning home during his basic military training, in addition to receiving a monthly military pension of R960,00, had all his expenses paid by the State. His mother reported that :

> The army have been absolutely fantastic ... they pay for everything, his medical bills, private physiotherapy, occupational therapy, speech therapy, transport to

> and from these activities ... he can have whatever is necessary, for life, and it won't cost us a cent.

Another mother (in the higher SES groups) has resisted applying for a disability grant as she associated this act with admitting that her son will not recover :

> We haven't applied because we always hoped ____ would get better sooner than he has and then we might be taking what someone else needs more ... I think for me to get that grant would be to .. well, to sort of admit defeat ..

A few caregivers in both SES groups reported financial outlay due to the brain-injured patient's low frustration tolerance resulting in his smashing plates, radios and furniture which had to be replaced. One mother commented:

> My phone account is R160 - R250 a month. He phones the whole world around. Now if I lock the phone he gets so furious he smashes it into pieces. He smashed two phones last week and he also tore out the back seat of my car.

1.3 Changes in social and leisure activities

All caregivers reported that the family's social and leisure activities had been severely curtailed. Of particular significance was the fact that they were unable to go on outings or on holiday together as someone always had to remain at home with the brain-injured family member. Family members also tended not to invite friends around as they either found that they were embarrassed by the brain-injured patient's demanding, irritable or possessive behaviour or alternatively, they found that friends were unable to accept or cope with the patient's changed appearance and behaviour. In addition, caregivers found they had little time to spend with friends as care of the brain-injured patient was so time consuming.

In cases where the brain-injured patient could in fact be left at home on his/her own, caregivers often felt guilty about going out. It is of interest in this connection that in the majority of families in the lower SES groups siblings were expected to relieve caregivers by staying at home with the brain-injured family member when necessary. However, in many of the white families within the higher SES groups, caregivers felt guilty about asking their other children to sacrifice their time. One mother observed :

> I wouldn't ask him to change his plans and stay in for the evening. Its not fair on him. He must not be made to feel he is being treated as a drudge and has to pay a price for something which is not his responsibility.

Security and safety of the brain-injured patient was of particular concern to caregivers in the lower SES groups, particularly those living in the black townships of Cape Town. One caregiver pointed out :

> We can't go out and leave her on her own because I worry all the time. The other day I came home and some skollies were trying to attack her. The skollies know she is not right in the head and they come and hurt her and steal. So we don't take any chances.

In lower SES group families the lack of a motor vehicle created major problems as very often the brain-injured person was unable to cope with public transport due to physical disability. The family was thus housebound and unable to visit friends or family.

2. IMPACT OF BRAIN INJURY ON FAMILY RELATIONSHIPS

2.1 Relationship of caregiver and brain-injured patient

The majority of caregivers complained of feeling trapped by the patient's extreme dependency. There was a lack of freedom to pursue their own interests, and their personal needs became submerged by the needs and demands of the patient. One caregiver, when speaking of her relationship with her son, summed it up thus :

> I feel some times that he almost wants to take over my body .. you know its a very strange feeling .. like he owns me and I am his prisoner. I get that trapped feeling .. when I feel he is even making decisions for me .. I feel like I am a shell of a person here to do his will.

The patient's constant demands of and complaints levelled at the caregiver was another common observation : "If I am one minute late to pick him up (from gym) he spends the next two hours complaining about it."

Many caregivers, particularly of those patients who were physically disabled, complained of feelings of exhaustion: "When my sister and her husband come to visit .. I used to enjoy that, but now they sit here (in the living room) and they talk and enjoy themselves but I'm not interested .. I mean I'm too tired, so I just go to bed."

Most caregivers admitted to being overprotective, tending to do things for the patient which, with some effort, he/she could manage for themselves. One caregiver observed :

> I think he has me running around a little bit more than is necessary. He asks me to do a lot, mainly because he knows I'll do it.

Another remarked : "Well, its difficult, because you see him struggling and then you say 'Well, look, I'll do it for you'".

Generally, however, in a busy household where other family members had to be taken care of, it was often easier, for the sake of expedience, to do something for the patient instead of waiting for him/her to laboriously complete the same task. One busy mother remarked :

> I think a lot of it is that I don't have very much time in the morning in trying to get everyone off .. and so I tend to do things for him to get them out of the way.

Although the above-mentioned problems are common to relationships where the caregiver is a mother to or a wife of a brain-injured person, the impact on the type of relationship differs. Additional specific problems were commented upon by caregivers who were mothers and by those who were wives.

2.1.1 **Caregiver as mother**

Whereas all the mothers in the lower SES groups denied being embarrassed by their child's brain-injury, a few of the mothers in the higher SES groups admitted to being embarrassed, particularly by their child's appearance and behaviour in public. One mother commented :

> I used to get very embarrassed and worry about what people thought about it .. and I wanted to explain, or put a little placard on the chair saying, you know, that it was a motor car accident and he wasn't born like that ..

The majority of mothers complained of their brain-injured child's intrusiveness in that he/she demanded that she account for every minute of whatever time she spent away from him/her or wanted to know full details of telephone calls she had made. A comment by one caregiver is pertinent in demonstrating the frustation she experienced with her son's lack of sensitivity:

> I was very cross with him the other day when an old friend came to visit and he insisted on sitting here from the moment she came in, even though I asked him to leave us for a while, until the time she left. And I said to him "you know, how would you feel if it was one of your friends visiting you and I insisted on sitting in on your conversation the whole time, barging into the conversation and trying to take over the conversation, how would you feel?"

A problem common to all caregiver mothers was the patient's impulsiveness and low frustration tolerance. One mother was particularly distressed by her son's impetuous response to her refusal to meet any one of his many demands by acting out impulsively and dragging himself into the road, throwing himself in front of the on-coming traffic. Another mother commented upon her son's argumentativeness :

> Before he was so lovable, he was my best child before the accident. He used to help me with things .. he could never do enough for me. And he never answered me back before .. but now he's so cheeky and he gets very cross so quickly if I don't do what he wants or agree with him about everything. Its not what I'm used to.

Sexually inappropriate behaviour caused several mothers distress in that their sons would make inappropriate sexual remarks and attempt to touch, kiss and fondle any woman they came into contact with. A mother remarked : "I have noticed at physio he will touch somebody's buttocks .. I find it totally abhorrent." Another mother was particularly traumatized when her brain-injured son made sexual advances towards her and expressed the desire to have sexual intercourse with her.

2.1.2 **Caregiver as wife**

All the wives caring for brain-injured husbands expressed sadness at having lost the man they had previously loved : "I have lost my husband and I have got back in his place a baby who is much more difficult than my youngest child."

Another wife commented :

> Before the assault ____ was a very good person, responsible, hardworking, he always took the family out .. ons het happiness gehad, ons het lekker saamgelewe. I had no complaints. We were very close. But now I have no feeling for him anymore because he's not the same person. I don't want to say this to him because it will hurt him but the truth is I don't love him anymore.

Some wives resented their husband's dependence: "He's totally dependent on me, he's like a child and I'm like a glorified nurse".

A lack of companionship was a common complaint where the husband no longer discussed matters of common interest with his wife or made plans with her for their future. He volunteered no information spontaneously and gave monosyllabic answers to his wife's inquiries about his day.

Low frustration tolerance, often resulting in angry outbursts, swearing and at times physical violence directed at them was reported by a number of wives. One wife revealed how she lived in constant fear of her husband who slapped, punched and pushed her around, enforcing her swift compliance with his (mostly unreasonable) demands. If she cried and showed him her bruises, he demonstrated complete lack of concern or empathy.

The patient's jealousy in the form of accusations of unfaithfulness and rejection were common complaints:

> He becomes furious if I speak to male friends of his. He's got this obsession that I'm having a relationship with one of them.
>
> If I hang up washing in the backyard, then he pulls the dirtbin over and sits on it right next to me until I have finished to make sure I don't talk to anyone over the wall.
>
> My husband gets very jealous. He always says : "I am a crock so now you have a boyfriend." I don't have time for a boyfriend!

Some wives have experienced social isolation due to their husband's possessiveness :

> We don't have many visitors anymore. I get so embarrassed because if he feels the people are staying too long then he calls me into the bedroom and tells me to sit with him. He says nothing, he just stands at the door and beckons to me. And I'm afraid not to obey him because otherwise he makes a scene .. he'll just lift me up and then push me out to the bedroom. And he won't let me visit my friends. He locks the door and hides the key so I can't go out.

Many wives complained of their husband's constant interference in their daily activities. One wife who had been a seamstress prior to her husband's accident, told of how he sat next to her while she did needlework telling her how to make the stitches and berating her for not doing them as he told her to.

Their sexual relationship with their husbands was a source of concern to all wives interviewed. Most wives confided that they no longer found their dependent and self-orientated husbands sexually attractive; their lack of empathy and sensitivity resulted in sex being an alienating experience for their wives. Husbands made sexual demands but often such demands and competency did not coincide. Alternatively, one wife described her husband's incessant demands for sex as

> unbearable .. he wants it all night long and I don't get any sleep. I can't stand it. I have tried to reason with him but he does'nt care .. he cares only for himself. He is not considerate like he was before.

A further complaint by caregiver wives was that they had to assume the man's role in the family. They felt the burden of having to be the breadwinner and be responsible for making all the decisions in the family, particularly with regard to the children and to financial matters. In addition they had to do jobs at home which they regarded as "men's work": "I feel frustrated because he can't help me empty the dirtbin or do heavy jobs at home .. I must do everything."

All wives felt they could not divorce their husbands. Feelings of loyalty and guilt were expressed, each wife feeling she had a commitment to care for her husband however difficult he was to live with : "I must look after him because no-one would want him now".

2.2 Caregiver's relationship with other family members

2.2.1 Marital relationship

Many caregivers reported that their child's brain injury had been a source of strain and had had a deleterious effect on their relationship with their husbands. The main area of contention appeared to relate to the wife's tendency to be overprotective in relation to their brain-injured child. One caregiver described the problem thus :

> ____ will start nagging my husband and it works on his nerves and then he will snap at him. And then I'll jump on him and then you see we get arguing and shouting at each other because I don't like the way he talks to ____.

Another caregiver described how her extreme tiredness and depression had affected her relationship with her husband : "I'm very cold towards my husband .. because I'm very tired." She felt resentful if her husband enjoyed social activities :

> They have a social club on a Friday and everywhere is drinks and so he also takes a drink and the moment he steps in that door I work myself up because I look at his face and I can see he has been drinking. I get so cross and aggressive. I don't think, I just shout and scream .. because I just sit here day in and day out looking at four walls, never coming across people and enjoying talking to them, laughing ... it just builds up and builds up and then it just bursts out.

The pressures of caring for a brain-injured child also substantially reduced the time which husband and wife spent together :

> We enjoyed being together .. we didn't even have to say anything to each other .. it was the fact that we were together. But now we find there's always ____. He always wants to chat and when we don't chat because we want a quiet time, he gets irritated. And wherever we go ____ goes with us. We find we have no privacy anymore. When we're discussing something private, suddenly ____ is sitting at your elbow and he must be part of the conversation, drawing attention to himself.

2.2.2 Maternal relationship with other children

All caregiver mothers reported that they felt they had far less time to devote to their other children due to the disproportionate amount of time they spent caring for the brain-injured child. This problem often led to resentment in the other children who felt neglected. One mother observed :

> My daughter feels that I give too much attention to ____ and she misses out. Sometimes she'll get mad and say : "Everything you do is for him. You've got a daughter as well you know".

Another mother in the lower SES group who is without transport and who is housebound due to her son's severe neurological and physical disabilities, observed with regard to her four year old daughter :

> I feel bad because M is suffering the most out of all of us. She feels so stupid amongst other children as she has never experienced what they have. She has never been to the beach or to a swimming bath. She hasn't experienced normal things that other children experience. And she doesn't have much attention from me because I am always busy doing things for ____.

A number of participants reported that their 'normal' children resented their brain-injured sibling when he upset the caregiver : "He's quite a sensitive child and he gets distressed when he sees ____ has upset me".

2.3 Brain-injured father's relationship with his children

The brain-injured father's <u>physically abusive behaviour</u> and <u>extreme irritability</u> with his children was a worrying problem for all married caregivers. One wife observed :

> They are terrified of him. If they say one word he doesn't like or they talk a bit loud or if he calls them and they don't come within a second, he thrashes them.

In certain of the lower SES groups where the wife was forced to work to support the family, the children were left in the care of the brain-injured father while she was at work. One wife described how her three year old child had had diarrhoea and when she arrived home he was covered in bruises on his legs and buttocks where her husband had beaten him for soiling his pants. Often, too, her husband would beat the children and then not remember having done so.

It was reported that brain-injured fathers often prevented their children from bringing friends home or refused to let them visit their friends thus causing their children to become socially isolated.

Many caregivers expressed concern that their children did not have a suitable father role model and that the physical violence they were subjected to would cause their children to become violent themselves.

One mother in the higher SES group observed that his father's brain-injury was a source of embarrassment to her son. He had for this reason been sent to boarding school and was insistent that he did not want his father to visit him there.

2.4 Brain-injured patient's relationship with siblings

Most of the caregivers were of the opinion that the brain-injured patient was extremely jealous of his brothers and sisters. One mother's explanation of this phenomenon was as follows :

> They were close before the accident but he's very anti her (his sister) at the moment. I think its a form of jealousy. He seems to bear a grudge against her because she can get about and be with young people. And she always offers to take him with her but he refuses. He doesn't want from her what he sees as charity.

Most caregivers reported that the patient's irritability and need for instant gratification of demands were the cause of a great deal of friction between him and his siblings.

In a few cases, caregivers reported an inability in siblings to accept their brother's defects and changed appearance. One mother observed that her daughter had moved out of the family home :

> She couldn't cope with the change in him. She always said : "Oh it'll just be a couple of months and he'll be back to normal." She couldn't accept it when this didn't happen.

A few caregivers in the higher SES groups reported that their 'normal' children were embarrassed by their brain-injured brother and no longer invited their friends around but preferred to go out to their friends' homes. Conversely, in the lower SES group families, the brain-injured patient appeared to be accepted by his siblings' friends.

3. CHANGES IN BRAIN-INJURED PATIENT

Although all caregivers reported some physical disability, the degree of disability varied according to severity of brain damage, i.e from gross physical disturbances, where the patient was fully dependent on the caregiver for every need, to patients who were fully independently mobile. Epilepsy was present in a few cases but contained with medication.

Other common changes reported by caregivers were forgetfulness, slowness, poor concentration, extreme fatigue and loss of initiative. Language disturbance was a problem in half the cases. One mother reported that although her son had obvious speech difficulties, he refused to acknowledge that these existed and refused to have speech therapy. In this connection some caregivers reported being very distressed by the patient's inability or refusal to face up to the reality of their disabilities. One caregiver, while discussing her wheelchair-bound son, observed poignantly :

> The thing that worries me particularly with him is that he hasn't come to terms with it at all. He's obsessional about doing exercises .. his whole idea is to become a model .. he goes on and on about this. Now, I mean, if you see his broken body ... how can he possibly think that in six months or so he's going to be a model? ..... I told him the other day that I couldn't stand it and asked him if he couldn't see that after three years all these ideas of his were simply not realistic and would not come true. And then he stopped for a while but now he's started again.

Although caregivers all reported varying degrees of the above-mentioned deficits in intellect, memory and speech, they observed that the marked changes in the temperament of the patient was their greatest concern. These included being emotionally labile, irritable, impulsive, suspicious, acting in socially inappropriate ways and general insensitivity, poor motivation, poor tolerance of frustration, irresponsibility and greater dependence on others. Many caregivers found it particularly difficult to accept the patient's egocentricity : "I've noticed since the accident he always brings the conversation to himself, to what he did and what he's going to be". Furthermore, caregivers felt distressed by the patient's apparent lack of insight into his/her often inconsiderate and childish behaviour.

The majority of caregivers reported that the brain-injured patient suffered from depression, manifested as feelings of worthlessness, withdrawal and tearfulness. One brain-injured husband had made a suicidal gesture : "because he said he couldn't handle the fact that he was so useless and hopeless .. he said he would rather die". Another wife observed : "While I'm at work he just sits there .. he does nothing, and when I come home, he doesn't greet, and I wonder what is wrong".

A particularly distressing change of temperament for one caregiver mother was her son's tendency, under minor provocation, to fly into an emotional rage expressed as an explosion of violent behaviour where he would destroy furniture and break windows and crockery.

4. CONTACT WITH MEDICAL PROFESSIONALS AND SOCIAL SERVICES

Physiotherapy and occupational therapy

Although all caregivers reported that patients had had some degree of physiotherapy and occupational therapy, only those families who had consulted private therapists were satisfied that their brain-injured family member had received adequate treatment. The majority of families in the lower SES groups reported dissatisfaction with the amount of therapy received after discharge from provincial hospitals and the often arbitrary way in which therapy was arranged. When therapy was arranged after the patient was discharged from hospital, lack of transport often prevented the physically disabled patient from attending. Although transport was available to and from large provincial hospitals, this was not the case where the patient was referred to one of the day hospitals in the Black or Coloured townships. One wife reported :

> Those exercises were at Guguletu and there is no transport from Langa and nobody to take him on the bus because I must work. He cannot get on and off so he stopped.

One caregiver described her frustation at being sent from pillar to post in her attempts to secure physiotherapy treatment for her brain-injured sister. She described how the patient, after discharge from hospital, was given a single appointment for physiotherapy for which transport was provided from Langa to the provincial hospital concerned. However, "after that they never made another appointment". When she complained to the medical staff in the outpatient department her sister was referred to an orthopaedic hospital in Retreat for physiotherapy and assistance with a walking stick. She recounts as follows :

> I hired a car and took her there. We had a letter from Groote Schuur. When we arrived the lady at the window said 'you can't come here without an appointment' ... so she gives me an appointment for the next week. And then I take a car again ... I am paying R25,00 each time return .. and we see a student doctor and she says 'we can't take this patient because this patient should have been treated at Groote Schuur'. She phoned Groote Schuur for an appointment. Then I get another car ... I asked for transport but they said I must get my own transport ...

The majority of caregivers in the higher SES groups reported satisfaction with the physiotherapy and occupational therapy patients have received. However, private physiotherapy at a cost of R380,00 to R400,00 a month is way beyond the means of those families in the lower SES groups. However, one patient in the lower SES groups had received a sum of money from a charitable organisation which paid for 30 sessions of private physiotherapy. However, lack of transport prevented this severely disabled patient from attending these sessions until his father's employer made provision for transport and a driver to convey the patient to Diep River twice a week. By way of contrast, a patient in the highest SES group received physiotherapy in the privacy of his home.

Certain of the patients in the lower SES groups had been referred to a work assessment unit, although it appears that such referrals were not routinely arranged but only occurred after they had attended the hospital for some unrelated complaint.

The majority of caregivers advised that no-one had shown them how to handle the patient when they were discharged from hospital. In those families where the patient received private physiotherapy, the physiotherapist demonstrated these skills : "She showed me how I could handle him by transferring him from the bath to the chair and so on ... she really helped us a great deal".

In informal discussions with occupational and physio- therapists, it was universally felt that treatment of brain-injured patients placed too great an emphasis on physical recovery and that not sufficient attention was devoted to the psychological aspects. Often referrals for physiotherapy were made for patients with chronic disability where little could be achieved. It was felt that little could be done to restore facilities that were essentially lost. No consideration was given to what the person would do for the rest of his/her life or how he/she could best capitalize on what they in fact had. Moreover it was felt that there should be greater liaison between doctors in neurosurgery outpatient departments and other disciplines.

Speech Therapy

Only two of the patients in the higher SES groups had received speech therapy although the majority had some language impairment.

Social Services

Caregivers in the higher SES groups had had little or no contact with social workers or social welfare agencies as there had been little need for these services apart from the arranging of disability grants. However, in the lower SES groups, all families had had contact with social workers who had arranged disability grants for the patients and social welfare for the children where the brain-injured patient had been the breadwinner. In one case, however, the wife of a severely brain-injured patient had received social welfare payments for her two small children for 11 months, whereafter she was advised by the department concerned that these payments were being discontinued. No reason was given for the cessation of the welfare grants. Another family had received food parcels for three months after the accident. Social workers also provided some counselling, particularly for working-class families :

> The doctors didn't explain what was wrong. It was only the social worker, Mrs. F, she was very nice. She sat us down and explained how ___ will be and told us not to react when she gets cross, so we understood. She explained that she will not be perfect like before so we were able to accept that.

The majority of caregivers reported some degree of dissatisfaction with the inadequacy of services available for severely brain-damaged patients, and felt that if there were better services in the community they would be less stressed. One caregiver lamented : "No-one cares about head injuries".

Psychiatric Services

Although several patients in the higher SES groups had been psychometrically tested, the majority of caregivers reported that neither the patient nor the family had had any psychiatric intervention. One caregiver who was receiving psychotherapy had been attending such therapy privately prior to her son's accident. Most caregivers felt that they would have benefitted from some form of therapy. Many caregivers expressed the view that they would value information on whether they were handling the patient correctly and whether or not they were being overprotective. They also felt that it would be useful to have help in coping with the patient's irritability and demanding behaviour as they often felt guilty when they reacted but felt "at the end of (their) tether". One caregiver wife expressed a desperate need for help in learning how to live with her characterologically changed husband. In a few families in the higher SES groups the family doctor was providing psychological support. Two patients who were prone to violent outbursts were being seen regularly in psychiatric departments where they received medication in order to control violent behaviour. However, these patients had not been placed on a behaviour modification programme and families had not been counselled on how to cope with the patient's violent outbursts.

Neurosurgery out-patient treatment

All caregivers expressed dissatisfaction with treatment received in the neurosurgery outpatient department which they attended with the patient after he/she had been discharged. One mother explained :

> Its a waste of time to sit there the whole day .. the doctors don't really examine him or do anything. When I have some complaints, they don't really tell me whats wrong.

Another mother was more specific:

> I took him a couple of times to out-patients but they only asked me a few questions, not him .. you know they looked at him as he was sitting in the chair, they didn't touch him or feel anything or ask him questions. I found that really it wasn't worth it because I would take him, I would find parking which was a hassle, have to get him and the wheelchair inside and we would be there practically the whole day and I'm not sure of the value of it ... psychologically it didn't do me any good because I was tired and depressed when I got home and thought, well what was it all about?

Contact with doctors

Although the majority of caregivers felt the medical care their brain-injured relatives had received had been adequate, they felt that communication between clinicians and themselves had been poor. Virtually all interviewees felt that the doctors had given a far gloomier prognosis than had in fact proved to be the case. With the exception of the two Black caregivers interviewed who indicated that the doctors had not offered them any explanations, all caregivers were told that the patient would remain "a vegetable". All caregivers reported feeling very distressed by this communication: "I believed them but it was very hard to hear. And I think I gave up after that and didn't expect anything." Another mother, although admitting to feeling "very upset and hopeless" on being told "you can expect a vegetable and what you get on top of that is a bonus", defended the doctors' actions:

> Now, having gone through all the stages of ___'s recovery, I realise they can't tackle it any other way because they can't tell you something and say in six weeks he'll probably be so and so because at that stage you're clutching at straws and you believe what you want to believe.

One caregiver admits that she did not ask any questions because "I didn't want to know, I wasn't ready. But now I want to know".

5. MANIFESTATION OF STRESS

In the caregiver

Although the majority of caregivers reported that their health had been negatively affected as a result of the patient's head-injury, these reports were subjective and it was thus not possible to be certain of cause and effect. However, those reporting an illness were asked whether they had suffered from it previously and also whether they attributed it to the stress resulting from the patient's head injury. Over half the caregivers judged themselves as feeling depressed. Symptoms of depression included initial and terminal insomnia, early morning wakening, weight loss and weight gain, depressed mood, tearfulness, extreme tiredness and diminished ability to concentrate. A mother of a quadraplegic, severely brain damaged son said :

> I can't sleep, I can't think properly and I'm so forgetful. I'm not interested in food and I get tired very quick. I used to be very energetic but now I don't feel like doing anything.

Anti-depressant medication had been prescribed for a few caregivers who all reported not having been on such medication at any stage prior to the brain-injury.

Extreme irritability was a common problem. One mother described her feelings :

> I was a much gentler person before the accident. Now I tend to get cross, or irritated, quicker than I used to. You know if I've had a particularly irritating day with ____ , if he's been terribly demanding and calling "mom" for everything - some times as many as 50 times a minute - and not even trying to do it for himself, I find I get to the end of my tether .... then I resent anyone else who makes demands on me and I snap at my family.

Hostility and resentment towards other family members was a cause of distress for some caregivers. One caregiver mother confided that she was afraid her marriage would end in divorce due to her frustration :

> I can't help it. I am frustrated of course just sitting in this house day in and day out looking at four walls, never coming across people and enjoying talking to them, laughing ... it just builds up and builds up and then when he comes home it just bursts out.

Common somatic complaints, particularly of caregivers in the lower SES groups, included chest pains, breathing difficulties, dizziness and bouts of diarrhoea, whereas in the higher SES groups the main somatic complaint was of constant tension headaches.

Anxiety, particularly when they thought about the future, was a common complaint of most caregivers. Where the caregiver was a mother, the concern centred around who would look after the patient once they had died or were too old to care for him. Conversely, caregiver wives were anxious about facing a future with a brain-injured spouse : "I don't know how I am going to live out my life with this man". In those cases where caregivers stated that prior to the injury they were prone to anxiety, they all stated that their "nervousness" had increased to a large extent since the injury.

A further manifestation of stress was one caregiver wife's admission that since her husband's accident she had resorted to alcohol to alleviate her anxiety.

A few caregivers felt they had become withdrawn since the brain-injury and thus welcomed the decrease in social activities : "I don't have much to say to anyone anymore. I think mentally I have gone downhill because I don't have the time or the inclination to keep myself intellectually stimulated anymore".

All caregivers admitted to feeling guilty when they snapped at the brain-injured patient. In addition, one mother felt devastated by feelings of guilt when she was obliged to "drag" her violent son into psychiatric emergency to be sedated :

> It sometimes takes eight porters to hold him down and they are rough ... its like he's an animal. And he screams for me ..... it makes me feel terrible and I cry and cry.

In other family members

Caregiver wives reported symptoms of anxiety manifested by their young children since their husband's head injury. One mother described clinging behaviour in her youngest child who was "terrified" of being left at home with his father while she went to work. Nail-biting, enuresis and social withdrawal in children were also reported by these caregivers. Another wife, in the higher SES group, reported that her teenage son had had to be sent to boarding school as she was unable to control his "wild" behaviour. (With regard to the reporting of behavioural and emotional problems in children by caregivers, the researcher is aware that it is impossible to assess to what extent these problems were prevalent prior to the injury or related to factors other than the brain-injury).

Manifestations of stress in siblings of the brain-injured patient seemed to centre around certain siblings' inability to accept their brain-injured brother's changed demeanour and appearance.

In those families where the caregiver was particularly depressed, other family members tended to find excuses for spending a great deal of time away from the home.

6. COPING MECHANISMS

When discussing the coping strategies employed by families, and particularly caregivers of brain-injured patients, the socio-economic status of the family had an obvious bearing on the repertoire of coping mechanisms available. Families in the highest SES groups were able to employ servants to assist with the physical care of the patient and in addition, the presence of such additional caretakers released the caregiver wife or mother to pursue activities outside of the home. A mother observed :

> My maid has been fantastic. She adores _____ , they get on so well. She loves wheeling him around. I feel quite relaxed about going to work because I know she is here to take care of everything.

Again, demonstrating reliance on paid help, a wife explained:

> We have a boy who has worked for us for 22 years and he's here to help _____ out of the swimming pool. He baths him too because I can't lift him. And if he falls, there's no ways I can pick him up, he's a very heavy man, so he helps me in that way.

With the assistance of their employees, these caregivers were thus able to work or to pursue interests held prior to the injury : "I go to the theatre with a girlfriend or I walk with members of the botanical society. And I go overseas every year."

In addition, sufficient funds made it possible for the brain-injured patient to attend a gym and other activities which were stimulating and thus contributed to the patient being less irritable and demanding.

For families in the lower SES groups without financial resources, there was a far greater reliance on family members to assist in reducing the caregiver's burden. To this end reassigning of roles in the family was common. So, for instance, in one family one married sister looked after her brain-injured brother for some months while she was pregnant and thereafter, another sister who had just completed her schooling looked after him for a time. His younger brother, too, had certain duties in relation to his brain-injured sibling such as dressing him in the mornings before going to school, feeding him at meal times and helping him to the toilet. This sharing of the responsibility of care meant that no one family member felt the burden was entirely theirs.

In addition, members of the extended family periodically looked after the brain-injured patient for a time, thus affording the caregiver a rest or allowing her to go on holiday.

Although assistance from social services or the general public was limited, certain charitable and welfare institutions rendered some assistance at a nominal charge. For instance, in one family a severely brain-injured son was taken on daily outings once a week. In another family someone from a charitable organisation was sent from Monday to Friday to bath and dress the quadraplegic patient, for which service a nominal charge of R18 monthly was rendered (based on the amount of the disability grant available to that patient). In a few cases, where the patient was completely bed-ridden, placement in a home for a temporary period of, say, a month, gave the caregiver a much needed rest. However, waiting lists were long and in addition, this facility was not available for black families.

All caregivers who were employed said that work was a distraction and the time spent away from the brain-injured family member enabled them to cope more effectively with him when at home. The wife of a characterologically changed spouse said that although she worried a great deal about her children being left with her, at times, violent husband when she was at work, she felt like a free soul ("'n vry voel") at work. She felt that going to work and having contact with others protected her from severe depression.

Religious conviction as a coping strategy appeared to play an important role for many caregivers. All caregivers who described themselves as holding firm religious beliefs felt that religion had played a major role in their being able to cope with the brain-injured patient : "The only thing that got me through was faith in God". Moreover, religious conviction assisted the caregiver to accept the situation. One caregiver who described herself as "very religious", explained :

> I accept that this is God's will. I have got a lot of faith .. God will always help me. And you know, when I'm upset I sing hymns to myself and then I feel better.

In some cases, the church (or mosque) had in addition provided some material assistance to those families who were stuggling financially. Furthermore, the church was often an important source of social support. Several caregivers took the brain-injured patient to church with them where they were readily accepted. Regularly arranged visits by church members to talk with the patient often released the caregiver for a period of time, allowing her the freedom to pursue her own interests for a couple of hours a week.

Support from husbands, where the caregiver was a mother, was of great importance to the majority of such caregivers : "I feel that because I've got _____ (husband) I can manage; without him it would be hell." Not only could her husband release the caregiver from some of her tasks in caring for the brain-injured son on weekends and in the evenings, but he also provided an essential receptacle for venting her feelings. In this respect, caregiver mothers who had the support of their husbands appeared to be in a somewhat less isolated situation than that experienced by wives of brain-damaged husbands in that, in the former circumstance, there was someone with whom to share the burden. In this connection, a divorced mother felt extremely distressed that she had had to bear the burden of caring for her brain-injured son on her own. For her, supportive psychotherapy had been essential in assisting her to cope.

Turning to others, especially extended family members, for support and encouragement, was a coping strategy employed by most caregivers : "My family visit a lot and they're always there for me to share my problems with". In the lower SES group families, caregivers relied heavily on extended family for financial assistance.

In lower SES group families, the support of neighbours and friends was particularly important : "I have got a lot of friends around here. If I need to go out I can just go to one of them and say "just stay with ______ for a while". And if I feel bad, then I talk to my friend across the road". Although some caregivers in the higher SES groups felt they did not want to impose upon their friends or neighbours, one mother observed : "My friends have been absolutely fantastic. Some times they take over the fetching and carrying and give me a day off". Some caregivers described how they got support from others in a similar situation : "Talking about my problems with ______ helps to make me feel better." In this connection, one caregiver said that realising there were others who were in a more desperate situation than her own made her more able to accept her situation.

Information-seeking in the form of reading up about head-injury enabled a few caregivers in the higher SES groups to acquire a better understanding of the patient's difficulties.

Most caregivers felt that keeping busy prevented depressive rumination about their situation : "If I feel depressed, I just get on with the housework, or knit or do something which takes my mind off things". For a few caregivers, simply crying as an emotional catharsis was regarded as a palliative for releasing tension and stress.

A few caregivers told of using humour and laughter as a coping strategy as well as employing cognitive measures such as trying to see the positive side of the situation. In this respect a few caregivers felt that a positive aspect of the brain-injury was that the family had become closer : "The family sort of drew into a tight knot after ____'s accident and we've remained close like that". One mother observed wryly : "I think its taught the whole family a lesson ... I don't think any of them would ever drive too fast".

All caregivers said they coped with the patient's irritability by trying to ignore it. With certain patients, however, reasoning with them had the desired effect. However, in families where the patient's low frustration tolerance was likely to lead to violent acting out, caregivers found the best way of coping was to comply with all his demands.

Most caregivers confided that, although this proved difficult, they were making an effort not to be overprotective and found that this lessened the burden of care somewhat. Thus caregivers were insisting that patients fed themselves and encouraged them to dress themselves and take responsibility for small jobs around the home.

Furthermore, setting limits for the patient was another strategy for reducing the stress experienced by the caregiver. One mother observed :

> Initially I tended to fuss over him all the time, doing everything and thinking of him as a child. Now I find, over the last year, I have begun to treat him much more as an adult .. you know a person who has got to fit in with the other members of the family. I think its healthier if he realises that every member of the family has a time and place and they need me as well.

While some caregivers were clearly depressed and felt hopeless about their situation, others regulated their emotional distress by minimising the patient's disabilities and behavioural changes or used denial of emotional distress in order to gain a sense of mastery : "I don't really worry about it because its happened and I can't change things, so what's the point of upsetting myself."

Most caregivers observed that they tried to "take each day as it comes" and not to think too far ahead as their burden then became unbearable. Thus, some days were very stressful and others, by comparison, were reasonable.

DISCUSSION

The two major aims of this study were the elicitation of relatives' subjective perceptions of the stressful impact of brain-injury on the family as well as the ways in which the family coped with this impact. It is felt that these aims were achieved in that the findings have produced rich and detailed descriptions of how relatives personally experienced living with a brain-injured patient, expressed in their own words, where they were able to emphasize what they themselves found important.

The findings reveal that all the relatives of the severely head injured patients comprising this study regarded the head injury and its sequelae as constituting a major stressful event for which they had been unprepared (Pearlin's (1982) "unscheduled event"). The impact of the head injury continued to cause upheaval in their daily lives resulting in chronic strain (Kessler, 1985; Pearlin, 1982) even two or more years after the event. Allowing for the limitation that the accounts given were subjective impressions and perceptions of relatives whose premorbid mental state was unknown to the researcher, caregivers were unanimous in their perception that their lives had changed drastically as a result of the head injury.

The main source of distress experienced by caregivers related to characterological changes in the patient, confirming the findings of previous studies (Panting & Merry, 1972; Thomsen, 1974; Oddy et.al. 1978; McKinlay et al. 1981). Although many changes in temperament were reported, of particular difficulty for relatives were those changes manifested as extreme irritability giving rise to emotional lability, an inability to control belligerant behaviour, and increased egocentricity coupled with loss of empathy and sensitivity. These changes correspond with the first two categories of Lezak's (1978) classification of characterological changes. Thus, two years or more after the injury, stress experienced by relatives of severely brain-injured patients related to emotional rather than physical symptomatology (Brooks, 1984; Thomsen, 1974). The extent to which emotional sequelae were secondary to frustration arising from physical handicap rather than the brain-injury per se is of course not certain. Relatives appeared to be realistically assessing the patient's disabilities at this stage and thus, a particular source of concern was anxiety for the patient's future welfare when caregivers were no longer able to care for him/her.

Although the findings reveal that all family relationships were adversely affected by the presence of the brain-injured patient, the burden was most keenly felt by the caregiver who was responsible for the daily needs of, and was most involved with, the patient. The caregivers were all women and, with the exception of one case, were all the mothers or spouses of the brain-injured patients (who, with the exception of one case, were all male).

In most cases, the caregiver had been obliged to make major changes to her lifestyle and the extent of these changes, particularly where they involved role changes, appeared to have a direct relationship to the stress she experienced in caring for the patient. Thus, mothers of adult children who had, immediately prior to the injury, been able to pursue their own interests or a satisfying career, were required to give up their interests and activities in order to care for their brain-injured children. The care of a severely brain-injured adult child was for them analogous to caring for a small dependent toddler, requiring constant physical care, vigilance and patience. The caregiver mother was thus obliged to return to a stage of her life that had passed, sometimes many years ago. However, in her new role as caregiver to a brain-injured adult, the burden of care was not going to diminish as it had in the case of her young children who became independent with increasing age. Caregivers who were wives had also been obliged to make drastic role changes, often becoming the sole family breadwinners in addition to caring for their brain-injured spouses and families at home. In addition, they were obliged to assume all the responsibilities and obligations associated with parenting and they alone carried the burden of all major decision-making concerning the family.

Panting and Merry (1972) and Thomsen (1974) have commented on the relative vulnerability of different types of family relationships, finding that the husband-wife relationship is less stable under the stress of a head injury than the parent-child relationship. A simple explanation for this is that where the brain-injured family member lives with his/her parents, there are two people to share the burden, but a married patient only has one spouse, and when the spouse has to cope with children as well as the brain-injured person, the burden becomes compounded (Oddy et al. 1985). The findings reveal that wives of brain-injured spouses felt isolated and lonely as they had lost the companionship of their husbands as well as interpersonal relationships with friends. In this connection, Lezak (1978) points out that the spouse lives in a 'social limbo' as she does not have a partner with whom to participate in social activities, but is nevertheless not free to acquire one. And, although she has lost her 'mate', she cannot mourn "decently" as he is still physically present, even though he is a stranger to her now. Moreover, she cannot divorce him without incurring feelings of guilt and for fear of social condemnation. Further sources of stress for wives related to frustrated sexual and affectional needs and concern about the brain-injured spouse's often violent reactions to their children.

Mothers of adult brain-injured children experienced a somewhat different problem to wives in that there was a breaking down of parent/child boundaries. Thus, adult brain-injured children became intrusive and sought intimate details of their mother's discussions with friends and demanded that their mothers account to them for time spent away from them. Thus, some caregiver mothers felt as if the brain-injured child was "taking over" their bodies. In other cases, however, the caregiver mother had become involved in an intense dyadic relationship with the brain-injured patient while her husband and other children were isolated outside of the "magic circle" (Shapiro, 1983).

Siblings of mentally handicapped children are considered to be a "population at risk" (San Martino & Newman, 1974; McConachie, 1986) and it is postulated that siblings of brain-injured patients should be regarded as equally vulnerable. Not only are they directly affected by their brain-injured sibling's characterological changes and disabilities, but parents are often unable to assist them in adjusting to these changes because they are themselves struggling with their own emotional reactions. In addition, some siblings in this study were required to cope with their own role changes in having to bear some of the responsibility for the care of their brain-injured brother. In some families, tension between parents further disrupted family stability and generated stress for other family members. It was apparent that where specific inter-family relationships were vulnerable prior to the head injury, difficulties increased post-injury and these relationships became increasingly disturbed.

The value of social support as a mediator of stress was a component of this research. Thoits (1983) suggests that social support can be conceptualised as "coping assistance". The findings indicate that the majority of caregivers perceived formal sources of support as being inadequate. They were dissatisfied with existing social services, with hospital after-care and generally felt unsupported psychologically, corroborating results of previous research (Brooks, 1984; Oddy et al. 1978; Thomsen, 1974). Relatives were generally of the opinion that informational support (House, 1981) in the form of advice and information about the current status of the patient from medical professionals was deficient. Relatives thus appeared to rely upon informal sources of support to alleviate their burden, and more particularly on emotional support from an intimate source.

Emotional support is repeatedly cited in the literature as a correlate of emotional health (Leavy, 1983; Lieberman, 1982; House, 1981) and those caregivers who felt unsupported emotionally reported themselves to be more depressed and felt their burden was greater than those who were supported. In this connection, however, Kessler et al (1985) caution that people who are experiencing distress may also judge their social relationships more negatively. Nevertheless, emotional support was rated as an important factor in assisting relatives to cope with the stress created by the presence of the brain-injured family member. Of particular importance to caregiver mothers was the emotional and appraisal support (House, 1981) received from their husbands, in that they were able to ventilate their feelings about their role as caregiver and received approval from him for their performance in the new role. Of importance, too, was the instrumental support she received from him in assisting with the care of the brain-injured patient. For most caregivers, emotional support from family, friends, neighbours and the church alleviated stress. Consequently, those families who had been forced to relocate (to single-storied accommodation) keenly felt the loss of support from the old neighbourhood. In addition, instrumental support from the extended family in the form of financial assistance and occasional physical care of the patient in order to relieve the caregiver, was of particular importance to families in the lower SES groups.

Although it is apparent that an informal support system did in fact mediate the stress generated by the head injury in the families comprising this study, it is important to remember that social support is only one environmental resource for alleviating stress. Pearlin & Schooler (1978) suggest that economic, financial or political power also expand response options.

Coping responses generated by the individual caregivers and their families were determined largely by the coping resources available to them in the "external environment" (Shapiro, 1983).. Families in the higher SES groups had access to full-time servants, motor vehicles to convey the patient and adequate medical, therapeutic and recreational facilities for the head-injured patient. As a result, an enlarged repertoire of coping responses was available to these caregivers in that they were able to visit friends and enjoy recreational activities which afforded them a respite from the burden of caring for the patient. These particular problem-focused coping strategies (Folkman & Lazarus, 1980) were not available to families in the lower SES groups and there was thus a greater reliance on the support of extended family and friends in the community to alleviate the burden of caring for the patient. All caregivers reported making use of emotion-focused coping mechanisms (Folkman & Lazarus, 1980) to regulate emotional distress. They relied on religious beliefs, cried, laughed and focused their efforts on controlling their daily stress by setting concrete limited goals. Most caregivers were fairly realistic about the problems they faced with the brain-injured patient at two or more years post-injury and it seems that emotion-focused coping was often considered the only way of accepting what would otherwise be an intractable situation. However, if being realistic about the permanence of changes in the patient was too threatening for caregivers, the moderation of such emotional stress was achieved by minimizing the patient's disabilities or by simply denying their own distress. Prigatano (1985) suggests that denial of the effects of brain-injury can be viewed as an ego-protective coping strategy.

A significant finding in this study was the view of all employed caregivers that their work was a major factor in enabling them to cope with the impact of the patient's head injury. In this connection, Thomsen (1974) points out that "working is more than production, it is also a great chance of establishing contact between people" (p.183). In addition, the time spent at work afforded caregivers a break from the brain-injured patient. In those cases where the severity of the patient's brain-injury required caregivers to be physically present without relief, a high level of depression and symptoms of anxiety were reported.

Although all families comprising this study had been affected by the patient's head injury and its sequelae, the families in the lower SES groups experienced additional problems not experienced by the higher SES group families. Bearing in mind that most families in the lower SES groups were racially disadvantaged, social security and social services were regarded by these families as hopelessly inadequate. Disability pensions and grants were seen as insufficient and securing payment thereof appeared to be uncertain and capricious. The disparity between the benefits attributable to the different racial groups is illustrated by the monthly amounts paid in each case : White, R251; Coloured, R195 and Black, R150 (official figures supplied by Cape Mental Health). In addition, the findings reveal that inequality and randomness was manifest in the services available to the different groups creating further frustrations for families in the lower SES groups. Relatively well-off families were able to provide their own transport, whereas poor families had to rely on such transport as was provided for them. Transport to major provincial hospitals appeared to be reasonable, but when the patient was referred to a day hospital in a Black township, no transport was offered even though the distance to travel was the same or greater. Black families thus suffered the double disadvantage of having to provide their own transport to day hospitals and having to find the wherewithal to pay for it. It was thus apparent that families of brain-injured patients who were racially and socio-economically disadvantaged were objectively subjected to chronic stressful conditions, and subjectively perceived themselves to be additionally stressed by their circumstances.

Supporting previous research (Bond & Brooks, 1976; Brooks, 1984; Fugel-Meyer & Fugel-Meyer, 1988) the rehabilitation services available to all the patients comprising this study were failing to meet their needs or those of their families. There appeared to be a concentration on physical handicap while little support was being provided for the families as they tried to cope with severe family disruption and the emotional sequelae of the brain injury. Although it is repeatedly suggested in the literature that the major problems for relatives of brain-injured patients relate to emotional rather than physical sequelae, the only interventions offered to the brain-injured patients in this study were of a medical rather than a psychosocial nature. The findings demonstrated a need for continuity of care where marital and parental counselling formed part of the routine after-care of brain-injured patients. In addition, patients clearly needed help with understanding and accepting their deficits and social difficulties and learning to compensate for them in the best way possible.

CONCLUSION AND RECOMMENDATIONS

This investigation examined the stressful impact of brain-injury on the family of the patient and ways in which family members coped with the stress generated by the injury.

This research has been largely exploratory in nature, the findings having implications for the management and counselling of families of brain-injured patients. The study may be said to have two limitations. Firstly, the small number of subjects militates against making definitive statements, but some interesting trends and patterns were found which have heuristic value for future research into the effects of head injury on the family. The second "limitation", which it is argued is in fact the strength of this study, is its qualitative nature. Most of the studies in the area covered by this research have thus far been quantitative and have used symptom check-lists or questionnaires to collect data from relatives relating to changes in the patient and which were then compared with the level of distress in the relatives as measured on various mood or adjustment scales. The purpose of this study was not to examine stress levels in relatives but rather to attempt to gain an indepth understanding of the everyday life of relatives living with and attempting to cope with a brain-injured family member, an understanding which is often missed in quantitative studies. The study demonstrated that the subjective state of the relatives interviewed was one of considerable strain and this finding has implications for therapeutic intervention with, and management of, brain-injured patients and their families.

In the course of the study, it was apparent that "brain-injured families" (Brooks, 1984), while experiencing stress, were feeling the lack of support from formal sources. The provision of more appropriate services for all brain-injured families, irrespective of socio-economic status or race, is an urgent need and should be addressed. More particularly, in order to provide effective follow-up of patients once they have been discharged from hospital, it is essential that there is adequate liaison between doctors in neurosurgical out-patient departments and other disciplines in order that the patient can receive the best and most appropriate treatment at the various stages of his/her recovery. Clearly, some workable rehabilitation scheme for all severe head injury survivors and their families which includes the capacity to deal with social and emotional difficulties is required. It is apparent that families would benefit from supportive counselling and practical advice on the management of the patient and this is an area of deficit which needs to be addressed.

In addition, the structural inequality between the different racial and socio-economic groups clearly needs attention. This is of course part of a much broader problem within our society. However by ensuring that the personnel involved in dispensing the services that are available are empathetic and sensitive to the difficulties experienced by disadvantaged families, much could be done to alleviate their distress.

Clearly, services must be properly and effectively co-ordinated. The appointment of one person to co-ordinate the practical problems facing the brain-injured family would seem to be important. Such a person could assist in securing the financial benefits to which the family is entitled, ensure adequate follow-up and management of the family, while taking account of the structural problems facing disadvantaged groups, and would thus be in a position to render assistance in addressing all levels of the problem facing the family.

An adequate multi-disciplinary rehabilitative programme is clearly called for. It is suggested that such a unit should be comprised of services provided by the State as well as those provided by voluntary and community-based organisations which are state-supported. In order to make the provision of such services cost-effective and appropriate, it is suggested that multi-disciplinary rehabilitation units are community based, thereby best serving the needs of the brain-injured family once the patient is discharged from hospital.

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APPENDIX I

DEMOGRAPHIC DATA AND DETAILS OF INJURY

Date:

Patient's name:

Age of patient:

Marital status of patient:

Informant's name:

Age:

Marital status:

Relationship to patient:

Address:

Rented or owned:

Does your house/flat present any problems for patient (ie. lack of space, toilet, steps)?
Please specify:

Have you had to make alterations because of patient's injury? Please specify:

Who lives at home with the patient and informant:

Occupation of head of household (if patient, then pre-injury):

Before the injury, was the patient in regular work?

Is the patient at present working?

Household income:
  Before accident/assault:
  After accident/assault:

Do you own a motor vehicle:

Educational level of patient:

Date of injury:

Circumstances of injury:

How injured :

In home :
At work :
MVA : pedestrian :
MVA : passenger :
MVA : driver :
sport :
assault :
"fell" :
other/uncertain :

Details of injuries:

How long in hospital:

How long was P.T.A.:

What was G.C.S. on admission:

How long unconscious:

Culpability of patient:

Had patient been drinking at the time of accident:

Is there a compensation claim pending:

If No, was there ever one:

If Yes, when was it settled:

What was the settlement:

Has the informant, prior to the accident, suffered from any disease, illness or "breakdown".
If so, please specify: