

**PERCEPTIONS OF AFRICAN FAMILIES ABOUT TRAUMATIC
BRAIN INJURY: IMPLICATIONS FOR REHABILITATION**

by

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submitted in part fulfilment of the requirements for the degree of

MASTER OF ARTS IN CLINICAL PSYCHOLOGY

in the

DEPARTMENT OF PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

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NOVEMBER 2000

The financial assistance of the Centre for Science Development (HSRC, South Africa) towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at, are those of the author and are not necessarily to be attributed to the Centre for Science Development.

DECLARATION

I declare that PERCEPTIONS OF AFRICAN FAMILIES ABOUT TRAUMATIC BRAIN INJURY: IMPLICATIONS FOR REHABILITATION, is my own work and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.



Signature

(Mr. Mota Thomas Mokhosi)

03/03/2001

Date

DEDICATIONS

This dissertation is dedicated to all families who shared their inner-most experiences about TBI courageously with me.



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ACKNOWLEDGEMENTS

I am deeply indebted to the following persons and an organisation. However, few are named here while scores remain nameless. They have all made this project a success.

- My supervisor, Prof. Kate Grieve, for her patience, encouragement and meticulous guidance, I am profoundly and eternally grateful.
 - Prof. A. P. Venter (Unin-Qwa), Xoli Mvoko and Thandaza Msimang for their encouragement to finish the race against all odds.
 - All family members who showed support and encouragement when it was difficult
 - The University of the North for everything it did to empower me.
 - My two sons, Motloli and Nele for their resilience and my niece, Motsheoa, for just being there.
 - My wife, Mongy for being patient with me and being there when I needed her most.
- Lastly, to Modimo le badimo ba Taung, who gave me the courage to continue against all odds

SUMMARY

The study aimed at giving a thick description of African families' experiences, views, cultural beliefs and interpretations of traumatic brain injury (TBI), and making recommendations for rehabilitation. It was conducted from the qualitative research paradigm, adopting a phenomenological research method. Twenty-two pairs of participants (patients and their caregivers) were interviewed about their perception of TBI. The semi-structured interviews were conducted at the participants' homes in Sesotho, and where necessary in their home languages.

The consequences of TBI were found to follow universal trends (Oddy, 1984). However, participants' perceptions, as shaped by their experiences, views and cultural beliefs, were found to be unique. On analysing the gathered data, using inductive data analysis, it was found that African families' interpretations of TBI were based on beliefs about witchcraft, thwasa, Satanism, ancestral anger and God's wish.

Based on these findings, rehabilitation services in the form of education, advocacy, networking and family therapy are recommended.

KEY TERMS

African families; Traumatic brain injury; Phenomenological approach; Qualitative interviews; Glasgow coma scale; Rehabilitation; Traditional healers; Witchcraft; Ancestral anger; Social networking

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CHAPTER 1

INTRODUCTION

The rate of survival of people with moderate to severe brain injury has increased dramatically over the past decades in all countries, and especially in urban centers with effective trauma evacuation and neuro-surgical services. It has been estimated that approximately 200 of every 100, 000 people in the United States incur traumatic brain injury (TBI) (Lezak, 1995; Naugle, 1990). In South Africa, particularly the Johannesburg area, the anticipated number of new cases per 100, 000 for the population as a whole is 316 (Nell & Brown, 1990).

Although brain injury is a significant medical problem that warrants intensive study to determine any pattern of occurrence that might in turn suggest means by which those injuries could be prevented or at least their effects reduced, and ways in which those injured individuals could be rehabilitated, little has been done, especially in the case of disadvantaged communities.

The following section is devoted to the epidemiology of brain injury.

1.1. Epidemiology Of Brain Injury: A Comparative And Cross-cultural Overview

There are several types of accidents and activities that result in brain injury. Among the most common and significant are the following, motor vehicle accidents(MVA's), falls, sports and recreation mishaps, home accidents, assaults, work/industry accidents, glue sniffing and cerebrovascular accidents(CVAs)(Jansen, 1989; Jansen, Richter, Griesel & Joubert, 1990; Lezak, 1995; Naugle, 1990; Nell & Brown, 1990).

Motor vehicle accidents account for approximately half of all brain injuries, both in South Africa and elsewhere (Nell & Brown, 1990; Naugle, 1990). In countries like China and the United States of America, it is reasonable to conclude that, because of the fewer number of high speed roads in urban areas, fewer people are injured in the course of road accidents. The greater tendency to rely on public transportation in the form of unserviced taxis and buses in South Africa, particularly among Africans, makes it possible for the larger number of people to be injured in the course of an accident (Nell & Brown, 1990).

Falls are the second leading cause of brain injury, occurring frequently among the very young and the elderly. Falls are followed in incidence by assaults and injuries resulting from sport and recreational activities like horseback riding, boxing, baseball and rugby to mention a few. Assaults predominate among the poor and unemployed and account for the majority of brain injuries in urban settings (Naugle, 1990). According to Nell and Brown (1990), assaults on the head account for most cases of brain injury among Africans.

As alluded to above, many people get injured daily. So the next section is about the services available for these individuals and their families to help them re-integrate into their communities.

1.2. Current Services Available To Traumatically Brain Injured Individuals And Their Families

Typically, traumatically brain injured individuals are admitted to general hospitals, where specialised rehabilitation facilities are not always available (Delehanty & Kieren, 1998; Dr. Watts, personal communication, July 23, 2000).

Some of these hospitals have introduced rehabilitation programs which seem to be superficial and often ineffective, mainly because they are not run by dedicated, knowledgeable and committed staff. These programs become ineffective mainly because they are only patient oriented, and exclude caregivers who should be helped to understand the behaviour of the traumatised relative (Fuji, Hanes & Kokuni, 1996).

On discharge from hospitals, many of these individuals, particularly those with limited financial resources, do not have access to private rehabilitation facilities. Injured individuals and their families who stay in major centers like Johannesburg, Cape Town and Durban have access to support groups like Headway, where they can get more information about TBI. Unfortunately, those who stay in rural areas have no access to information. It is on the basis of the lack of information and/ or incorrect information that injured individuals and their families do not start preparing for a changed family life in advance. Lack of information and/or access to resources

is a stumbling block in the rehabilitation process (Delehanty & Kieren, 1998; Dr. Watts, personal communication, July 23, 2000; Headway, personal communication, July 23, 2000).

1.3. Definition Of Concepts

This research examines the perceptions that African families have about traumatic brain injury (TBI) and the implications these perceptions have for rehabilitation. It is therefore appropriate to define the key words: perception, African and traumatic brain injury (TBI). Von Foerster (cited in Keeney & Morris, 1985, p. 548) suggests that we view perception as “closer to an act of creation, as in *con*-ception, than to a passive state of affairs, as in *re*-ception”. In similar vein, Gordon (1993, p. 31) defines perception as “...the process by which each person senses reality and comes to a particular understanding or view. It is an active process that results in different people having somewhat different, even contradictory views or understanding of the same event...”. Baron and Byrne’s (1997) and Penrod’s (1983) definition of social perception is congruent to Gordon’s (1993) definition of perception. They define social perception as processes through which people attempt to understand others and events unfolding in their social environment. The meanings that can be attributed to these events and behaviours may differ from one person to the other, due to among others, cultural factors. Perception presupposes two activities, namely, attention and organisation. Due to the fact that each person is structure-determined (Leyland, 1988; Maturana, 1975; Maturana & Varela, 1992) each has his/her different concerns, perspective, unconscious biases and supposed vantage point. Each attends to those aspects of the phenomenon which fit with who s/he is and organises understanding congruent to that structure. Though perceptions are observer-dependent (Leyland, 1988; Maturana & Varela, 1992) and constructionistic (Gergen, 1991; Von Foerster, 1984; Von Glasersfeld, 1984; Woolfolk, 1992) in nature, they are embedded within a particular historical framework. Perceptions are frames that are put within a larger framework in order to give organisation and meaning to phenomena. It is important to note from the above that perception is not objective and that all observations have equal validity. They are valid in that they are specified by the structure of the observers in conjunction with what that observers’ interaction with the medium allows. It is on this basis that Maturana insists that all realities which people

bring forth are legitimate (Maturana & Varela, 1992; Dell, 1985; Johnson, 1993; Simon, 1985). The words perception and view (in singular and/or plural forms) are used interchangeably in this research.

The word African, is used in this study to designate Kintu/"Bantu"-speaking peoples. Though the word "Bantu" would seem to offend more readers, it vividly distinguish the participants of this study from other population groups. Examples of Kintu/Bantu speaking peoples are Sotho, Tswana, Xhosas and Zulus to mention a few (Nell & Brown, 1990).

The third concept, traumatic brain injury(TBI) is defined as a slightly less imprecise concept than head injury, that excludes cases of only superficial damage to the face or head, for example, screens out facial cuts and broken jaws, but includes only those cases with damage to the central nervous system (CNS)(Powell & Wilson, 1994; Wilson & Powell, 1994). The most suitable definition of TBI is given as "...an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment" (Brown, Darling, Hardman, Lonseth, Rieger, Rousseau, Seiler, Ward, Weber & Wright, 1997, p.20). This damage could be due to a blow to the head or rapid acceleration/deceleration of the head, or penetration by a foreign body of skull fragments. Brain injury in general could either be diffuse (caused by acceleration and/ or deceleration forces) or focal (caused by a foreign body penetrating the brain) (Powell & Wilson, 1994; Wilson & Powell, 1994). This study is about both focal and diffuse traumatic brain injuries that result in partial or/and total functional disability or psychosocial impairment.

The section that follows looks at the rationale for undertaking this study.

1.4. Rationale For Undertaking The Study

As alluded to earlier, this study seeks to discuss the views/perceptions African families have about traumatic brain injury (TBI) and its consequences. It also looks at the implications these perceptions have for rehabilitation. In an attempt to discuss these perceptions the following questions will be addressed:

- What are the perceived effects of brain injury on the family ?
- How do families (i.e care givers and patients) understand TBI ?
- What is the role of culture in the perceptions families have about TBI ?
- How could these families be rehabilitated ?
- What are the required rehabilitation strategies for the patients and their families ?

The choice of African families as the focus of the present study is motivated by the dearth of literature on African families' perception of brain injury, particularly in South Africa. Though researchers like Jansen (1989), Jansen et al., (1990) and Nell and Brown (1990) conducted similar research among Africans, they did not focus on the perceptions of families, but on issues like severity of brain injury, glue sniffing as a cause of brain damage and the epidemiology of head injury, respectively. This study, therefore, attempts to close the gap left open by these and many other researchers in South Africa.

Apart from this chapter, there are five more chapters organized as follows:

Chapter 2 is a literature survey which provides a theoretical background to this study. In particular, it explains what TBI is, discusses correlates of TBI and areas of functioning that are known to be vulnerable to TBI, for example cognition, emotions and personality to mention a few.

Chapter 3 describes systems theory and its application to the family system. It also discuss the experiences and views of significant others (spouse, parents, siblings, child(ren)) about brain injury and its consequences in relation to the survivor. The chapter is concluded by looking at the influence culture has on perceptions, particularly, about TBI and its consequences.

Chapter 4 looks at the research methodology used in this study, its suitability and how its validity is assessed, the selection of participants, data gathering techniques and data analysis technique.

The findings are presented in Chapter 5 and are organised according to the common themes

that emerged during the interviews and the recursive and inductive data analysis.

The final chapter, Chapter 6, is the discussion. It relates the findings to the existing literature. The implications of the perceptions African families have about TBI are also discussed and some recommendations for rehabilitation are made. In this chapter the author takes a meta-position in examining the role he played in this research, examined the limitations of the study and suggests possible follow up studies. The study is concluded by summarising the main points.

CHAPTER 2

LITERATURE REVIEW

The aim of this chapter is to explain what TBI is. In the process of doing so, it expands on the severity of TBI, its outcome, and the time scale of recovery. Furthermore, it discusses correlates of TBI. Finally, it discusses the cognitive, emotional and behavioural deficits associated with brain injuries that affect family functioning.

2.1. What Is Traumatic Brain Injury

It is sometimes a difficult task to distinguish between brain injury and head injury. This task is made difficult by perceptions that every head injury results in brain injury (Naugle, 1990). Nevertheless, brain injury is a concept used to screen out cases of only superficial damage to the face or head. For example, it screens out facial cuts and broken jaws, but includes only those cases with damage to the CNS (Central Nervous System). This damage could be due to a blow to the head, rapid acceleration/deceleration force or rapid penetration by a foreign body of skull fragments (Powell & Wilson, 1994; Wilson & Powell, 1994). Therefore, TBI is more than just a head injury. It entails damage to and/or functional impairment of the brain. Some researchers have chosen to infer that traumatic brain injury results from any head trauma that involves any combination of clinical criteria such as loss or alteration of consciousness, post traumatic amnesia, skull fracture, neurological deficits and seizure disorders to mention a few (Levin, Benton & Grossman, 1982; Naugle, 1990). Depending on the severity of TBI, survivors could be mildly, moderately or severely impaired in various spheres of functioning.

2.2. Classification/Severity Of TBI

In order to assess the severity of brain injury, the following measures, among others are used, namely, alteration in the level of consciousness, post traumatic amnesia, and physiologic and radiologic evidence, to mention a few (Naugle, 1990; Jansen, 1989; Levin et al., 1982).

2.2.1 Alteration in the level of consciousness

This measure has been the traditional benchmark of definitions of brain injury. While the majority of head injuries do result in some alteration in the level of consciousness, alteration in the level of consciousness may not occur with some brain injuries (Levin et al., 1982). In some cases a blow to the head, provided it is of sufficient magnitude may produce a haematoma which may only produce an alteration in the level of consciousness with expansion of the haematoma. Therefore, alteration in the level of consciousness is not a necessary or sufficient event to define the presence of brain injury. Nonetheless, level of consciousness does provide one very important data point in terms of establishing the magnitude and degree of brain injury. It also provide some predictive information regarding outcome (Naugle, 1990; Jansen, 1989).

The Glasgow Coma Scale (GCS) is used to quantify level of consciousness. This scale evaluates among others, the three components of wakefulness independently of one another, viz. stimulus required to induce eye opening, the best motor response and the best verbal response. Using the GCS criteria, coma is defined as the inability to obey commands and failure to utter recognisable words. Such a definition is applied to patients with GCS score of 8(eight) or less. The worst score of 3(three) on the GCS indicates no eye movement(opening) to any stimuli, including pain, and no verbal utterances, to mention a few. A maximum score of 15(fifteen) occurs when the patient can spontaneously open his eyes, and demonstrates normal orientation to time, place and person. Generally the classification of TBI is as follows: the score of less than 8 is severe impairment, 9 to 12 is moderate impairment and 13 to 15 is mild. Level of consciousness alone is not a totally reliable predictor of the severity or outcome (Naugle, 1990; Jansen, 1989; Teasdale & Mendelow, 1984).

2.2.2 Post traumatic amnesia

Post traumatic amnesia (PTA) is another indicator of brain injury that provides an index of its severity. PTA should not be confused with coma and recovery from coma. PTA assumes that the patient is alert and functioning, and has recovered the comatose state but has persistent and severe

deficits in retaining new information and processing new memories (anterograde amnesia). The other form of memory impairment is retrograde amnesia (i.e. inability to recall events that happened before the accident). Levels of severity of PTA range from very mild (less than 5 minutes) to mild (5 minutes to 1 hour), to moderate (1 hour to 24 hours), to severe (1 to 7 days), to very severe (more than 7 days). In general, the longer the PTA, the more severe the brain injury (Naugle, 1990; Jansen, 1989; Teasdale & Mendelow, 1984).

2.2.3 *Physiologic and radiologic evidence*

With the advent of imaging procedures such as Computerized Axial Tomography (CT scan) and Magnetic Resonance Imaging (MRI), in addition to the traditional electroencephalogram (EEG), patients with head injury can be evaluated in terms of the anatomical or electrophysiological basis of traumatic injury. CT scan and MRI studies may demonstrate the presence of cerebral contusion, edema and other structural lesions that may have occurred. Therefore, the dimension that needs to be added to the definition and the description of TBI is whether the patient shows any physical evidence of neurological injury on direct examination using the CT scan, MRI or EEG, in addition to the alteration of the level of consciousness and the presence/absence of PTA. Physical examination of the patient may also show clinical syndromes such as aphasia and paralysis to mention only two (Naugle, 1990; Lezak, 1995; Teasdale & Mendelow, 1984).

2.3. The Outcome Of TBI

With the development of clinical neuropsychology, a need arose for a limited number of clearly defined categories of outcome to which patients could be allocated at a series of specific times after injury. The Glasgow Outcome Scale (GOS) was devised to meet this specific need. This scale summarises the overall social outcome, without considering the separate components of the disability/impairment. It consists of five levels (categories) of outcome, each of which has distinct characteristics. However, only four levels of outcome are applicable to surviving patients (Jennett, 1984; Lynch, 1984). These levels are as follows:

Death (non-surviving patients).

Vegetative state- This description is restricted to patients who show no evidence of psychologically meaningful responsiveness. Vegetative patients breathe spontaneously, have periods of spontaneous eye opening when they may follow moving objects and may swallow food placed in their mouths. Inexperienced observers, particularly patients' families, are likely to interpret these behaviors as evidence of the recovery of voluntary activity (Jennett, 1984; Lynch, 1984).

Severe disability- This level describes patients who are conscious but need the help of another person for some activities of daily living. This ranges from continuous dependency (for feeding and washing) to the need for assistance with only one activity, such as dressing, getting out of bed or going outside for shopping. It should be noted that dependency is due to a combination of physical and mental (psychological) impairments. Most of the severely disabled are either hospitalised or cope at home with the support of attentive relatives (Jennett, 1984; Lynch, 1984).

Moderate disability- People described by this level are sometimes called “ the independent but disabled”. This is because they look after themselves at home, get out and about and use public transport with relative ease. However, some activities engaged in previously, either at work or in social life are no longer possible by reason of either mental or physical deficits, often both. Some patients in this category are able to return to work (Jennett, 1984; Lynch, 1984; Zarski & Depompei, 1991).

Good recovery- Good recovery often characterises mild brain injury. However, this category indicates the capacity to resume normal occupational and social activities, although there might be some physical and mental (psychological) deficits. Patients may not have resumed all their previous activities and in particular may not be working (Jennett, 1984; Lynch, 1984; Zarski & Depompei, 1991).

2.4. Factors That Affect Outcome

There are many factors that have been found to affect the outcome of TBI. Della Sala and Logie (1997), Lezak (1995) and Tate (1998) all agree that the following factors affect outcome, namely, age,

premorbid mental ability, education, premorbid personality and social adjustment, to mention a few.

2.4.1. Age

Research has established that the older the brain injured, the worse the outcome. The opposite holds for younger adults. Related to this is the fact that older people stay longer in the hospital while younger ones do not. It is believed that brain plasticity makes it easier for younger patients to adapt and cope with life challenges (Della Sala & Logie, 1997; Lezak, 1995; Tate, 1998).

Related to age is the severity of the brain injury. Though some young patients with severe brain injury recover comparatively well, older patients (+50 years) generally do not. This is evidenced by among others, the fact that most if not all, are unable to return to work or assume a relatively normal social life (Della Sala & Logie, 1997; Lezak, 1995; Tate, 1998).

2.4.2. Premorbid mental ability

Premorbid ability level is closely related to academic achievement. It is not surprising to find that its relationship to mental functioning after brain injury is high, so high that in studies of war injured veterans, premorbid ability was the best predictor of posttraumatic ability (Lezak, 1995).

On reviewing findings of a significant relationship between estimated or known premorbid ability and the level of cognitive impairment with brain injury, Satz (cited in Lezak, 1995) offers a "threshold theory" which postulates that the amount of "brain reserve capacity (BRC)" represents structural and/or physiological brain advantages, such as size, redundancy of interconnections or disadvantages. BRC advantages will be reflected in higher premorbid scores on comprehensive ability tests, higher educational levels and better functioning, even with brain damage, no matter the severity (Lezak, 1995). According to Lezak (1995, p.308) "...the concept of BRC was hypothesized to account in part 'for the rate and degree of recovering after the acute phase of injury' and for differences in the emergence of symptoms..."

2.4.3. Education

The effect of education on the outcome of TBI is potent and pervasive. Education can so greatly influence performance that poorly educated but cognitively intact persons may score lower than mildly impaired but better educated patients (Lezak, 1995).

Education has been positively associated with outcome. The better educated the patient, the better the outcome. Comparatively speaking, educated patients adapt better because they have bigger cognitive resources from which to draw. According to Prigatano and Parsons (1976) brain damage can attenuate education effects, or education may have positive effects for some brain damaged patients.

2.4.4 Premorbid personality and social adjustment

Premorbid personality contributes both directly and indirectly to the kind of adjustment a patient makes following TBI. Direct effects are evident since premorbid personality characteristics are often not so much changed as exaggerated by brain injury. Anger outbursts, impulsivity and other forms of acting out and disinhibited behaviour can be symptomatic of frontal lobe damage in a premorbidly benign and well socialised person. When these disruptive behavioural traits have been present premorbidly, they do appear to contribute to some of the severe behavioural disturbances (Lezak, 1995).

The indirect effects of premorbid adjustment may not become apparent until the patient needs emotional support and acceptance in a protective but not institutional living environment. Patients who have conducted themselves in an emotionally stable and mature manner are likely to be supported through critical personal and social transitions by steadfast, emotionally stable and mature families and friends. However, patients with marked premorbid personality disorders or asocial tendencies are more likely to lack a social support system when they need it most. Many of this group have been social isolates, and others are quickly rejected by immature and/or recently acquired spouses, alienated children and opportunistic and/or irresponsible friends who want nothing

of a dependent patient who can no longer cater to their needs (Kaplan, 1990; Lezak, 1995).

2.5. Time Scale Of Recovery

Recovery is a dynamic process, and for how long substantial improvements may continue is a matter of debate. It is generally accepted that the first year after injury is the period of greatest recovery, slow for the next year and then flattens out, although it can not be said that there will be no further recovery after two years. There are isolated reports of dramatic recovery years after the injury. However, these reports lead some clinicians to hold out the prospects of significant recovery for longer than is realistic, and to put off too long the assessment of outcome. Maintaining unrealistic expectations tends to delay the acceptance by the patients and their families of the certainty that some degree of disability is likely to be permanent. This, in some way, postpones the taking of practical steps to adjust and to plan appropriately for the future. Patients and families who were told of the outcome at an early stage reflect better social adjustment because the disabilities/impairments have been accepted, and appropriate adaptations made. In some cases, recovery of certain functions depends heavily on the rehabilitation provided (Jennett, 1984).

2.6. Correlates Of Brain Injury.

Age, gender, socioeconomic status and other demographic variables like psychological disorders, delinquency and previous brain injury correlate with the incidence of head injury (Naugle, 1990). These correlates are discussed hereunder.

2.6.1. Age

There is enough evidence to show that brain injuries resulting from the spectrum of causes discussed previously are not distributed randomly across the age range, but rather are more likely to occur at given ages than others. A pronounced peak of closed head injury is between mid-adolescence and mid-twenties. This peak is consistently reported (Hubert, 1995; Naugle, 1990).

Studies conducted in America and Britain have shown that most survivors of brain injury are between 15 - 25 (Naugle, 1990). Other studies to the contrary found the peak age to be 25 - 44 years (Fife, Faich, Hollinshead & Boynton, 1986). The latter studies are in line with Nell and Brown's (1990), and Jansen's (1989) findings in South Africa that susceptible people are males between 25 - 44 years. Age is also related to the length of stay in hospital and the outcome. Older survivors tend to be hospitalised for a long time and their outcome is poor (Levin et al., 1982; Naugle, 1990).

2.6.2 Gender

Males consistently predominate in hospital admissions and deaths due to head injury. The male-female ratio is as high as 4:1 during middle adolescence and early adulthood, due to the number of young males who are injured in assaults and motor vehicle accidents. Males who get injured in the course of athletics, sports and recreational events outnumber females by a big margin (6:1) (Levin et al., 1982; Naugle, 1990). In South Africa, Nell and Brown (1990) arrived at the same conclusion. However, some exceptions to this rather consistent pattern have been reported. For example, in the case of pedestrians and passengers of automobiles, females have been found to outnumber males. In addition to their greater incidence of head injury, males tend to incur more severe trauma and are more likely to succumb to their injuries than females (Levin et al., 1982; Naugle, 1990).

2.6.3. Race

In the studies conducted in America there is mixed information regarding the relationship between race and closed head injury. Other studies have failed to uncover any noteworthy differences in the rate of new cases between whites and blacks. However, others have reported a predominance of blacks in their samples, but several neglected to provide any information on the racial composition from which samples were drawn. Desai et al. and Whitman et al. (cited in Naugle, 1990) found the incidence rate among blacks to be approximately twice that for whites. They concluded that the higher rates among blacks are primarily attributable to the greater rate of trauma as a result of assaults in young males. Jagger et al. (cited in Naugle, 1990) are of the view that blacks are 49% more likely to suffer injury than whites. The higher rate among blacks in S.A. may be a reflection

of demographic factors. Many of these Africans injured are pedestrians: the victims of other's negligence or/and alcohol/drug abuse. The victims of interpersonal violence are also predominantly black (Jansen, 1989; Nell & Brown, 1990).

2.6.4. Social class

Many researchers have found and concluded that the incidence of brain injuries are inversely related to socio-economic status. In urban hospitals, head injury patients typically come from the lowest socio-economic strata of society, that is, the materially poor ones. Most of the injuries are caused by fights and motor vehicle accidents (MVA's). Though assaults are a common cause of brain injury among low socio-economic strata patients, sports-related injuries figure more prominently in the upper income groups (Levin et al., 1982; Naugle, 1990).

2.6.5. Psychological disorders, delinquency and previous brain injury.

Personal problems, disturbed social relationships, life stressors, psychological disorders and alcohol/ substance abuse have been associated with brain injury or accidents that cause them. There is an association between the occurrence of major life events which are by implication stressful, increased subjective stress and road accidents. For example, men who have accidents while alone tend to have experienced an excess of major events in the six months prior to the accidents. Since the commonest mode of transportation for Africans in South Africans is the taxis, it is important to note that accident prone taxi drivers are more likely to have divorced parents, a history of truancy at school, poor work records and sexual promiscuity (Levin et al., 1982; Naugle, 1990). It is in the taxis driven by such taxi drivers where a great number of Africans sustain brain injuries and others die. Adult head trauma patients tend to be young and have a history of antisocial behaviour, a higher incidence of disturbance of family life and a high incidence of domestic and industrial accidents (Levin et al., 1982).

Sims (cited in Naugle, 1990) speculates that brain injuries precipitate accident proneness. To the extent that brain injury (trauma) results in impaired coordination and clumsiness or a loss of

confidence in activities requiring coordination, victims may be at greater risk for incurring additional injury. In effect the risk of brain injury appears to be greater among those already injured (Levin et al., 1982; Naugle, 1990).

It is noteworthy to realise that a number of investigations have uncovered marked hourly, daily, monthly and seasonal variations, during which motor vehicle accidents and other incidents occur (Naugle, 1990). In South Africa motor vehicle accidents happen during peak traffic hours, that is between 7 am - 9 am and 4 pm - 5 pm. Although accidents happen throughout the year, their rate is higher during Easter and Christmas months, especially when most people go on holiday.

The following section looks at the significant cognitive, emotional and behavioural deficits associated with brain injuries that affect family functioning.

2.7. The Cognitive, Emotional And Behavioural Deficits Associated With Brain Injuries That Affect Family Functioning.

When working with the families of brain injured persons, it is crucial to identify the nature and variety of cognitive and behavioural deficits that are likely to create stress and disrupt the family system. Some of the deficits, which Rosenthal (1984) believes are crucial but not exhaustive, are discussed here.

2.7.1. Presence of cognitive deficits

According to Rosenthal (1984) the most persistent deficits following traumatic brain injury are cognitive. Though significant recovery of formal intellectual function is observed during the first year post-injury, residual problems in maintaining attention, processing complex information, storage and retrieval of information, problem solving and inability to use conceptual and abstract thinking are often present, and generally present significant obstacles to the patients and families (Brooks, 1984b; Kinsella, 1998; Rosenthal, 1984)

Many studies have commented upon the poor performance of the brain injured on tasks involving memory and a general slowing of performance is common. Brain injured patients perform significantly worse on a variety of tests involving recall, recognition and relearning of both verbal and non-verbal material. Planning ability may also be poor. This is because they are unable to conceptualise changes from present circumstances, deal objectively with themselves in relation to the environment and adopt an abstract attitude (Brooks, 1984a; Lezak, 1986). The implication for this lack of planning is that these patients need constant supervision from significant others (Tate, 1998)

2.7.2. Disorders of communication.

A factor of great significance in the successful reintegration of brain injured patients into the family is an open, effective communication system. However, communication disorders such as aphasia, dysarthria (imprecise articulation, distorted vowels, monoloudness) and apraxia can impair the patient's ability to cope and communicate. They find it difficult to retrieve words, thereby making their speech slow. The other problem which is regarded as "non-aphasic" but which characterises the communication of head injured person presents in the form of talkativeness and tangential speech. This problem is tied to a lack of connected thought (cohesion). This implies that social interaction skills are markedly deficient, reflecting a disturbance in the use of language (pragmatics). The lack of cohesion in discourse may violate social context demands, reflecting a direct language disturbance or a cognitive and concomitant language problem. This has a negative impact on interpersonal interaction (Lezak, 1995; Marquardt, Stoll & Sussman, 1990; Rosenthal, 1984; Willmes & Deloche, 1997).

Thomsen (cited in Brooks, 1984a) noted that even months after head injury, there may still be indications of a reduction in expressive and receptive language ability.

2.7.3. Emotional changes

Some brain injured adults become more childlike and immature. They may demonstrate behaviour patterns reminiscent of childhood and adolescence. For example, they may display childlike dependency, crave constant attention, display inappropriate affect (e.g. labile) or even engage in violent temper tantrums. The significant others of patients may be dismayed and confused by their behaviours and express confusion as to the appropriate methods of managing them. However, these significant others may unwittingly contribute to the maintenance of these behaviour by providing attention and positive reinforcement when they occur. There may also be an impaired capacity of social perceptiveness, in which former powers of self-criticism are diminished or lost with associated development of egocentricity and loss of empathy (Bond, 1984; Lezak, 1995; Orto & Power, 1994; Rosenthal, 1984).

2.7.4. Psychiatric disorders

Often the accident results in cosmetic changes, such as scars and cranial defects, that greatly alter body image and self concept. The result of the recognition of loss of cognition and psycho-social functions and other rewarding activities is frequently an onset of depression which may be observed in the form of decreased activity level, self-derogation, negative affect, feelings of worthlessness, and occasionally suicidal ideation. The mere presence of depression may have a major impact upon the family, who feel impotent and frustrated. Brain injured persons who experience depression are likely to be more passive, dependent, and less productive, thereby imposing a greater burden on family members who feel a sense of responsibility for maintaining the emotional well-being of their loved ones (Levin et al., 1982; Lezak, 1995; Rosenthal, 1984).

Another psychiatric disorder related to depression is anxiety disorder. Anxiety reactions with or without phobic symptoms are characterised by tiredness, weakness, loss of energy and a presence of hypochondriacal concern. The other psychiatric disorder that can emerge after brain injury is schizophreniform psychoses. Psychiatric disorders may be the direct result of structural brain injury

or an indirect result, arising from the persons' perception of his/her limitations and problems. All these and other related psychiatric disorders are stressors to the whole family (Bond, 1984; Levin et al., 1982; Lezak, 1995; Rosenthal, 1984).

2.7.5. Frontal lobe dysfunctions

Patients with brain injury often display a constellation of behaviors identified as frontal lobe syndromes. Damage to the frontal lobes may result in a variety of behaviors including, among others, asponaneity, lethargy, flat or dulled affects, irritability and loss of initiative. There may also be a loosening of inhibitions, lack of regard for social goals and moral standards, and perseveration in speech and other activities. Because of persistent fatigue, significant others become irritated with them. Patients with frontal lobe syndrome need constant supervision and may be a considerable burden to family members. They also have the worst prognosis of all traumatically brain injured patients regarding their return to independent living and vocational productivity. These patients are characterised by an impaired capacity for behavioural control and self-regulation, producing impatience, impulsivity and restlessness. Their alcohol tolerance is also low, which is the case with all persons with diffused axonal injury to the brain (Bond, 1984; Levin et al., 1982; Lezak, 1995; Rosenthal, 1984).

2.7.6. Withdrawal from social contacts

Patients with brain injury, particularly severe ones, suffer a severe blow to their self-esteem on account of apparent physical or/and mental deficits, as well as a perceived loss of self-worth and identity as productive, well-functioning, competent individuals. Feelings of decreased self-esteem are reinforced by the loss of peer contacts and social relationships. It is not only peers who withdraw their support. Even relatives who rallied around the family on first hearing the news, withdraw their support as time passes and recovery slows (Rosenthal, 1984; Williams, 1991)

Brain injured adults often perceive themselves as different, handicapped, brain damaged and unattractive and as a result tend to isolate themselves or as alluded to previously, be isolated from

their peers in the community. They also isolate themselves because of communication difficulties. Because of this isolation the burden is on the family to provide meaningful, rewarding activities within the home setting. The stress experienced by family members who accept this responsibility is very great (Lezak, 1978; Rosenthal, 1984).

2.7.7. Inappropriate social behaviour.

As alluded to earlier, the behaviour of the brain-injured adult often resembles that of a young child/adolescent. It is interesting to note that many of these patients are unaware of the consequences and implications of their behaviour. These behaviours interfere with the social acceptability of the survivors. They are largely anti-social. However, only three prominent behaviour difficulties are discussed here.

2.7.7.1. Aggressive behaviour

Aggressive behaviors occurring following head injury are a result of reduced behaviour control and frustration. Typically, the patient with minor provocation, react with violent behaviour quite out of proportion to the eliciting event. This kind of aggressive behaviour is probably a consequence of damage to frontal lobe structures, for example, the limbic structure, which results in blunting of various social skills and a tendency towards inappropriate behaviors. The inappropriate behaviour is evidenced by enduring features of short temper, non-cooperation, abusive language and generally threatening or difficult behaviour (Lezak, 1995; Rosenthal, 1984; Wood, 1984).

2.7.7.2. Sexual behaviour

Uncontrolled or inappropriate sexual behaviour can be as distressing, even as threatening to others as aggression. It varies considerably in its nature and intensity and includes tactless attempts at intimacy, exposure and public masturbation (Lezak, 1995; Rosenthal, 1984; Wood, 1984). The presence of a constellation of inappropriate behaviors is a source of embarrassment and frustration

for the family. These problems are related to disinhibition resulting from impaired frontal lobe functioning (Orto & Power, 1994).

2.7.7.3. Attention seeking behaviour

Extreme forms of attention seeking are not a frequent legacy of brain injury, but when they occur they cause management problems which might be disproportionate to the problem behaviour itself. This problem behaviour is the result of loss of self-control. The reason for this is that often the behaviour appears bizarre, involving self-injury, screaming for no apparent reason or head banging. This creates, in many families a feeling of helplessness, or of being out of control in a situation which the patient seems to manipulate and command (Lezak, 1995; Rosenthal, 1984; Wood, 1984).

2.7.8. Inability to resume premorbid role within the family

Because of the cognitive, emotional and behavioural deficits discussed above, brain injured adults are usually prevented from successfully resuming premorbid roles within their families. In the marital relationship, it is often observed that the brain injured husbands who were formerly assertive partners become passive, or at times, aggressive and difficult (Johnson, 1998; Rosenthal, 1984).

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In addition, the severely injured persons are often unable to return to work. The most common vehicle each of us has through which to earn respect is work. In almost all societies, work is often the foundation of an individual's identity. This implies that the inability to resume premorbid roles in the family and in the society has a negative influence on one's self-identity, hence the depression and other related psychiatric symptoms (Rosenthal, 1984; Silver, Price & Barrett, 1991; Wood, 1984).

Conclusion

From the foregoing discussion, it is clear that TBI is experienced differently by brain injured persons. There are specific functions that become affected but the degree to which they are affected differs. The variability of TBI makes it possible for different families to experience and perceive TBI in markedly different ways. This means that the family environment plays an important role in the rehabilitation of injured members. After all, the importance of a stable home environment to rehabilitation often becomes crucial when determining whether a patient can return to the community or must be placed in a nursing home.

CHAPTER 3

THE FAMILY SYSTEM AND TBI

Building on the previous chapter, this one aims at putting the family of the TBI person within the family systems perspective. This is done by firstly discussing general systems theory and its offshoot, family systems theory. This is followed by the discussion of family systems theory applied to head injury, stages of family adaptation, impact of brain injury on the family systems, factors influencing perception and the impact of African families' beliefs system on understanding TBI.

3.1. General Systems Theory And Family Systems Theory.

Systems view looks at the world in terms of relationships. Systems are integrated wholes whose properties cannot be reduced to those of smaller units. Rather than concentrating on basic building blocks (units), the systems approach emphasises basic principles of organisation. All systems are wholes whose specific structures arise from the interactions with and interdependence of their parts. The activity of all systems involves a process known as transaction, that is, the simultaneous and mutual interdependent interaction between multiple components. This implies that systems are intricately dynamic in nature (Becvar & Becvar, 1996; Capra, 1983).

All living organisms, including human beings are integrated systems. Nevertheless, systems are not confined to individual organisms and their parts. The same aspects of wholeness and integration are exhibited by social systems, such as human families, and by ecosystems that consist of a variety of organisms and inanimate matter in mutual interaction (Becvar & Becvar, 1996; Capra, 1983).

Family systems theory emerged from general systems theory. Proponents of family systems theory regard the family, not the individual in the family, as the primary unit of analysis. Hill (cited in Maitz, 1991, p. 67) defines a family as "an arena of interacting personalities, intricately organized into positions, norms and roles". From the definition it is clear that the family is defined not in terms of the individual members but by the structural elements in the family system, which include norms, position, roles and the function and interaction of these elements.

It takes into consideration that though people are individuals, they are still parts of a system and that events in the system are interconnected and are part of a constant process of reciprocal influence (Bennum , 1994; Maitz, 1991).

From the above discussion at least three principles of family systems theory can be deduced. They are, the principle of non-summativity which states that in order to understand the family, we have to pay attention to the interaction of the whole family, not individual members. The second one is the principle of wholeness which Watzlawick, Beavin and Jackson (cited in Maitz, 1991, p. 68) describe as “ Every part of a system is so related to its fellow parts that a change in one part will cause a change in all of them and in the total system”.The last one is the principle of homeostasis, which suggests that systems strive to maintain balance. However, balance does not imply a static situation but a situation in which a system is constantly evolving in order to meet its ever -changing needs (Bennum, 1994; Maitz, 1991).

3.2. Family Systems Theory Applied To Brain Injury.

According to Turnbull and Turnbull (1990, p. 79) “families exist in order to meet the individual and collective needs of family members in seven broad categories, including economic, daily care, recreation, socialization, self-definition, affection and educational\vocational”.Families will therefore be able to effectively carry out their duties provided there is no breakdown in the family system role. When the breakdown occurs in the form of brain injury, family interaction is affected and role changes occur (Maitz, 1991; Williams , 1991).

It is important to note that brain injury happens to the entire family, not just the injured person. A brain injury to any one member of a family system disturbs the homeostatic balance of that family system. The relationships within the family between all its members, including the brain injured, are adjusted in an effort to restore an equilibrium. Families differ in their ability to negotiate the new equilibrium (Kreutzer, Zasler, Camplair & Leininger, 1990).

The needs for care and assistance of persons who sustained brain injury and the costs of meeting such needs are substantial. As alluded to earlier, it thus affects not only the patient, but the individual's entire family system. The impact of brain injury is great for families and often

family members are more distressed than the patients, especially those who lack insight into their impairments. Ongoing difficulties that families encounter include emotional, personality and behavioural changes in their members with injuries, lack of information and appropriate services, financial burden and emotional strain due to prolonged care taking (Koscuilek, 1997; Tyerman, 1996).

As the family routine is tailored to meet the needs of the patients, the personal and social lives of family members often falter. For the highly dependent, family members may need to cut back or give up their employment because there is seldom adequate home care and few families can afford to employ professional nurses. Where employment is maintained, that is, if family members do not give up their employment, carers(nurses) may be preoccupied or too drained to apply themselves effectively. Families are normally left to cope with little medical, support if at all. For aging parents, there is the added worry about the patient's long-term needs (Brooks, 1984a; Tyerman, 1996).

In response to the reduced role of the patient, other family members may assume additional roles. Parents may revert to a familiar parental role but struggle under the additional strain. Spouses may have to take on a caring role for their partners and sole responsibility for their children, and in turn the children may have to take more responsibility for themselves. Such changes may evolve naturally and help the family in short-term coping with the effects of the injury. They may also change family functioning and prove difficult to reverse in line with the patient's progress. Often families are left to make adaptations with little, if any, professional guidance and support (Tyerman, 1996).

The role changes alluded to earlier are usually accompanied by severe stress. This reaction is understandable, bearing in mind that after a person has sustained brain injury, she/he is forever changed, and families mourn the person who was. This mourning occurs and reoccurs at significant times during the family's life cycle. It is important for anyone who works with families to recognise that each family is unique and has its own culture, values and personal history. Therefore every family experiences and responds to stress in its own fashion. Research has shown that cognitive and social problems of brain injured persons are more stressful on families than physical problems (Maitz, 1991; Williams, 1991). According to Williams (1991) the unfortunate

thing is that people with brain injury and their families are more often unaware of the short and long term problems that may occur and affect all of them, thus they are not prepared to manage these problems.

Families generally progress through several stages as they attempt to adapt to the initial crisis and the long term care of their injured member. These stages are discussed below.

3.3. Stages Of Family Adaptation.

Martin (1990) and Orto and Power (1994) among other researchers, agree on the following stages in family adaptation.

3.3.1. Shock

The onset of a traumatic brain injury has a sudden, unexpected and an extensive effect on the life of family members. They experience feelings of helplessness, numbness, being overwhelmed, confusion and at times the temporary loss of self-control. Shock is often intensified by the spectre of a member who is comatose and appears to be lifeless and unresponsive (Hubert, 1995; Martin, 1990; Orto & Power, 1994).

3.3.2. Denial \ Disbelief

As the shock fades, family members move into a phase of denial or disbelief about a member's injury. This is partly due to limited information or understanding as to what extent the patient will be impaired. They may deny the actual existence of an injury or as alluded to, the permanence of the disability. In other words denial may take the form of insisting that recovery will be complete. The unfortunate situation is that members may develop unrealistic expectations about the patient and set up a cycle of failure for themselves and the injured member (Martin, 1990; Orto & Power, 1994).

3.3.3. *Grief/ Sorrow*

When family members develop an awareness of the extent of the injury, they may experience a profound sense of sorrow. They grieve for the member who was. They come to grips with reality that an injury occurred and that its effect may be permanent. As members gradually realise that the injured will not be the same as they were pre-trauma, issues of blame, guilt, anger and depression emerge (Martin, 1990; Orto & Power, 1994).

3.3.4. *Adaptation/Reorientation*

This stage represents a period in which the family reaches some form of emotional equilibrium. Individual members adjust their life to meet care-giving demands, role re-allocation tasks and at times, family finance changes. For some families, adaptation is quick while for others it takes years. Therefore, adaptation is not a static, once off event, but is rather a very fluid process that may fluctuate over long period of time. However, other factors that have been identified as potentially influencing family adaptation include among others, age of the member who has the disability, number of other siblings in the family (in the case of sibling/ child injury), length and stability of the marital relationship (in the case of a spousal injury), parent's educational and religious background, and ethnicity (Martin, 1990; Orto & Power, 1994). Each ethnic group has its own language and shares a common genealogy, and by implication culture. Members of ethnic groups are totemic, that is, they have animals or plants, which they regard as their totem. The totem is the visible symbol of unity, of kinship, of togetherness and common affinity. Normally, groups sharing the same totem organise themselves in clans. Members of clans give each other all kinds of support needed to adapt to mishaps like brain injury (Mbiti, 1969).

3.4. **Impact Of Brain Injury On Family Systems.**

Gordon (1993, p. 31) defines perception as "... the process by which each person senses reality and comes to a particular understanding or view. It is an active process that results in different people having somewhat different, even contradictory views or understanding of the same event." Perceptions are therefore influenced by a myriad of factors, for example, educational level , religion and ethnicity and culture to mention a few. It follows therefore that perception is a

personal interpretation of events (subjective reality).

This section therefore looks at how various family sub- systems (holons)perceive brain injury. These sub-systems are, the survivor (patient), the parental sub-system, the spousal sub-system and the sibling sub-system. For the sake of this document, these sub-systems are discussed separately, but practically, they should be understood as mutually influencing each other, in line with family systems theory.

3.4.1. The survivor/patient

Many survivors of TBI have limited insight into their disability. As a result, when looked after by other family members they become angry, saying that they are viewed as being very stupid. For those who have insight, it is very embarrassing to lose control of their emotions and various aspects of their functioning. They often feel angry at themselves and regard themselves as insane and failures (Martin, 1990; Campbell-Korves, 1991). Other prominent characteristics are anger and frustration due to the fact that they are unable to do what they used to do. A significant number is emotionally labile. (Hubert, 1995; Lezak & O'Brien, 1990; Oddy, 1984).

They feel socially rejected and isolated when friends withdraw from them, and as a result they experience depression. Their involvement in sporting activities declines, which aggravates the feeling of isolation. Social isolation is related to two factors, that is, "confusion" and "verbal expansion", which Oddy (1984, p. 117) defines as "...a tendency to be forgetful and disoriented in time and place" and "... a measure of the degree to which a person is brash, outspoken and verbally aggressive" respectively.

Cognitive deficits may also have particularly disruptive effects on social and leisure activities. Memory deficits are related to loss of social contact. Those patients with gross intellectual loss have fewer social contacts because they can no longer relate to people they know on social level (Brooks, 1984a; Tyerman, 1996).

There is normally marked friction between the patients and their parents and/or their siblings and/or spouses. Physical deficits are not associated with family friction but they lead to greater

dependence upon the family. The changed body image due to physical deficits leads to, among others, depression and a feeling of worthlessness (Koscuilek, 1997; Tyerman, 1996; Wood, 1984; Zasler & Kreutzer, 1991).

3.4.2. *Parental sub-system*

If the survivor is a child, parents must try to understand the new child, whom they may find obstinate, uncooperative and displaying maladaptive behaviour. As a result some parents think it would have been better had the patient died because they would not be feeling guilty all the time. When the accident happened while parents were in the process of divorce, they interpret it as "God's wish not to divorce".

Patient's social immaturity is a source of concern for parents. A thorny issue is when they are promiscuous. Due to lack of understanding of head injury, patient's odd behaviour may be regarded as madness (Kramer, 1991; Lezak, 1986; Oddy, 1984). However, it should be noted that some patients engage in joint activities with their parents, and some parents often take their brain injured sons/daughters with them when they visit friends and relatives, or even to work. In some cases, this is an attempt by parents to compensate for the reduction in social contacts, while in others it is due to their reluctance to leave the patients at home unsupervised. A child's injury may place a burden on parents' relationship, especially if one parent gives more attention to the child than the spouse (Tyerman, 1996).

3.4.3. *Spousal sub-system*

Spouses often fulfil a caring and/or therapy role for an injured partner. However, faced with the task of adapting to long-term changes in the injured person as expectations of further recovery recede, spouses may review their roles and the future of their marital relationship. Where the spouses change, not just in physical and cognitive skills, but also in their personality, this may alter the relationship and threaten the viability of the marriage (Tyerman, 1996).

Where there is physical disability, the couple may have lost shared activities, like walking and dancing to mention a few. Where there are cognitive impairments, the spouse may miss former stimulating conversations, companionship and partnership, and where there are behavioural difficulties there may be social embarrassment and tension. Aggression is predominant in relationships where the patients lack awareness/insight and dispute difficult behaviour (Tyerman, 1996).

Spouses may find their caring roles incompatible with that of sexual partners, while crude language, socially inappropriate behaviour and poor personal hygiene are a major obstacle to reactivating sexual relations. Spouses often feel trapped in relationships which are no longer rewarding (Beaver, 1991; Orto & Power, 1994; Tyerman, 1996).

Spouses struggle to cope with the competing needs of work, their partners and their children. They may have little time if any, for their leisure and social needs, especially where the injured partner is not able to share responsibility. Loneliness and depression are also commonly reported (Martin, 1990; Tyerman, 1996).

3.4.4. Sibling sub-system

Immediately after the head injury, siblings may have problems with their sleep, concentration and appetite. They may be overwhelmed by a deep sense of anger that the injury happened to their sibling, guilt because they could not prevent the injury from happening and/or fear about the future. They find it difficult to relate well with their injured siblings due to their problem behaviours and communication breaks down. If the sibling got injured as a result of negligence, for example, drunken driving, siblings feel that the injury was God's punishment, not only to the survivor but to the whole family. At times the event may be interpreted as God's wish for the family to stay intact (Hardgrove, 1991; Hubert, 1995; Maurer, 1991; Sohlberg & Mateer, 1990; Wood, 1984).

3.5. Factors Influencing Perceptions Of TBI.

There is a host of factors that influence the way people experience, believe and interpret, that

is, perceive TBI. Nevertheless, only five such factors are discussed here, namely, level of education, lack of information, premorbid functioning level, family expectations and cultural factors, namely, sorcery and witchcraft, ancestors' role and God's role.

3.5.1. Level of education

The level of education of both the patients and caregivers plays an important role in the perception of TBI. The better educated the caregiver, the better the understanding of TBI and its consequences. On the other hand, the better educated the patient and the better insight s/he has, the better understanding of TBI and its consequences. A note of caution is that education should not be limited to academic achievements, but to include level of sophistication brought about by wisdom and prior exposure, as shown by the easy understanding of abstract concepts. It should be noted that culture shapes and is shaped by education (learning), through processes like, among others, acculturation, accommodation and socialization. It is important to note that more than eighty percent of black South Africans are illiterate. Therefore, their understanding of phenomenon like TBI may be limited. The situation could be aggravated by professionals not explaining the phenomenon in the patients' and caregivers' home language or interpreters failing to give a coherent and understandable explanations (Lezak, 1995; Williams, 1991).

3.5.2. Lack of information

According to Williams (1991), families often do not receive the information they need to plan for the long-term future of their families. They particularly do not receive information about the long-term consequences of brain injury. At the time of the injury, families believe that the episode of hospital care and recovery will be minimal. Often families do not know that their loved ones may have severe problems with attention, concentration, memory and problem solving, as well as changes in emotions, personality and behaviour, which are often the consequences of brain injury. Furthermore, families do not realise that the entire family system will experience ongoing stress, associated with, among others, financial, psycho-social and care issues resulting from the injury. As a result, brain injured patients and their families are unaware of the short- and long-term problems that may occur and affect all family members, hence they are not prepared to manage these problems (Bond, 1983; Williams, 1991).

3.5.3. Premorbid functioning level

How well the patient was functioning inside and outside the family before the injury influences the recovery process as well as family's perceptions. If the patient was a breadwinner or an achiever (academically and otherwise) before the injury, families expect them to function at the same level even after TBI. This is the result of the fact that most caregivers do not fully comprehend TBI (Lezak, 1995).

Traumatic brain injury poses many obstacles to return to work or academic life, not least because it commonly affect teenagers and young adults who are either still in training or just establishing themselves in their careers, with most of their working lives ahead of them. Loss of employment has a major bearing on the financial resources of both the patient and the family, particularly when the patient lives with a spouse and is a major breadwinner (Kosculek, 1997; Tyerman, 1996).

For those with severe brain injury, return to most former duties is in doubt. Without guidance and sometimes contrary to advice, some with limited insight insist on early return, inadvertently jeopardising the future of their jobs. On the other hand, for those with mild to moderate injuries, most return to work and academic life. Nevertheless, in the absence of specialist assessment many return too soon and struggle with post-concussion symptoms such as headaches, fatigue, poor memory and concentration and irritability. When these persist the patient may enter a downward spiral of self-doubt, anxiety and lost confidence (Oddy, 1984; Tyerman, 1996).

3.5.4. Family expectations

Each family member is expected to perform certain functions and duties, which Hall (cited in Louw, van Ede & Louw, 1997) calls developmental tasks. Even long after the traumatic injury, members are still expected to carry out their appropriate role and developmental tasks. A failure due to an injury destabilises the family system. It becomes very difficult for the family to accept that their member will not perform the expected roles any further. As a result they hang onto mystical explanations that make them ill-prepared for the worst experiences to come (Hardgrove, 1991). The rapid progress a patient makes early on after the injury heightens expectations.

However, families may find themselves on a roller coaster of expectations, with hopes for the future alternately raised and dashed as the patient makes progress or falls back (Williams, 1991).

3.5.5. *Cultural factors*

As alluded to earlier, cultural factors are divided into three sub-sections, namely, sorcery and witchcraft, ancestors' role and the role of God (religious beliefs).

3.5.5.1. *Sorcery and witchcraft*

For African peoples, sorcery stands for antisocial employment of mystical powers (Hammond-Tooke, 1975). Sorcerers are feared and hated in their communities. It is feared that they employ all sorts of ways to harm others and their belongings. They invoke spirits to attack or possess someone. Many African people feel and believe that all the various ills, misfortunes, sicknesses, accidents and tragedies which they encounter or experience are caused by the use of this mystical power in the hands of a sorcerer, witch or wizard. According to African people nothing harmful happens by chance; everything is caused by someone directly or through the use of mystical powers. For this reason, they resort to *inyangas/isangomas* and other traditional healers to supply them with protective objects. These objects may include articles on the roof or in the field, cuts, knots and medicine. These objects and many other rituals engaged in, secure a feeling of safety, protection and assurance (Beuster, 1997; De Velliers, 1985; Hammond-Tooke, 1989; Mbiti, 1969).

Witchcraft, on the other hand is a term used more broadly to describe all sorts of evil employment of mystical power, generally in a secret fashion. For Africans, the academic distinction between witchcraft, sorcery, evil magic and other ways of employing mystical power to harm someone or his/her belonging does not exist (De Velliers, 1985; Hammond-Tooke, 1989; Schreiter, 1985). A noteworthy point is that Africans believe witches/sorcerers are mainly women with an inherent power by means of which they can abandon their bodies at night and go to meet with similar people (other witches), or to, as Mbiti (1969, p.202) puts it "suck or eat away the life of their victims".

3.5.5.2. *Ancestors' role*

African ancestors are called by many names, for example, badimo, amadlozi and the living-dead. They are the closest links that man has with the spiritual world. They are bilingual; they speak the language of men, with whom they lived until they died; and they speak the language of the spirits and of God, to whom they are drawing nearer ontologically. They are still part of their human families and people have personal memories of them. Symbolically they return to their human families from time to time and share meals with them, however, symbolically. They inquire about family affairs and may even warn of impending danger or rebuke those who have failed to follow their special instructions, for example, thwasa or getting married to someone they do not approve of. They are the guardians of family affairs, traditions, ethics and activities. An offence in these matters is ultimately an offence against the forefathers who, in that capacity, act as the invincible police of the families and communities (Hammond-Tooke, 1989; Mbiti, 1969).

The spirits (badimo) possess men and are blamed for forms of illness like madness, epilepsy and accident/injury. The food and libation given to badimo are paradoxically acts of hospitality and welcome and yet of informing them (badimo) to move away. They are wanted and yet not wanted. If they have been improperly buried or were offended before they died, it is feared by the relatives or the offenders that they (badimo) would take revenge. This would be in the form of misfortunes, especially illnesses or accidents/injuries. If people neglect to give food and libation, where this is otherwise the normal practice, or if they fail to observe ancestral instructions, then misfortunes and sufferings would be interpreted as resulting from their anger (Hammond-Tooke, 1989; Mbiti, 1969).

3.5.5.3. *The role of God*

God has always been part of the culture and the tradition of African families. Long before the so-called western civilisation was brought to Africa and South Africa in particular, God was called, among other names, Modimo, Kumkani and Tlatlamatjholo.

Whereas sorcery and witchcraft are regarded as the main causes of individual diseases, injuries and other misfortunes, it is not uncommon to consider God as also responsible. Mental

disturbances tend to be blamed on the spirits, even if human agents may also be considered responsible. Some societies/communities hold that God has three different aspects, one of which is responsible for misfortunes among people. According to Mbiti (1969, p.44), these misfortunes are regarded as "God's will and message". God punishes people for their mischiefs. The sacrifices often made when a person is ill or after an accident imply that God is the cause and the relatives ask for pardon. In so doing they think God is the ultimate cause and they believe that he can avert or delay death (Mbiti, 1969).

Nevertheless, Mbiti (1969, p.45) says " On the whole, God is not blamed for calamities, misfortunes and sorrows which strike man. He is brought into a picture primarily as an attempt to explain what is otherwise difficult for the human mind; an explanation which also serves to comfort those struck by the particular form of suffering".

It is imperative to briefly discuss beliefs system of an African family and their impact on the perceptions of injuries.

3.6. Belief Systems Of An African Family And Their Impact On Perceptions of TBI

Earlier on in this chapter, a western conception of a family was given. It is therefore proper to give an African conception and look at how it influences perceptions of an injury.

For African peoples, the family has a much wider circle of members than the word suggests in the western tradition. In African societies the family includes children, parents, grandparents, uncles, aunts, brothers and sisters who may have their own children, and other immediate relatives. In many cases, there are what is known as extended families. The family also includes the departed (dead) relatives and unborn members who are still in the loins of the living. All these family members are buds of hope and expectation. When an injury, particularly TBI strikes, it shatters the hope and expectations and caregivers and other relatives might find it difficult to accept. When TBI strikes either a married or unmarried member, it means the death of the unborn and the diminishing of the family as a whole (Hammond-Tooke, 1975; Mbiti, 1969).

In an African family, each member is expected to carry out certain chores, for example, men

should defend their fields against enemies and bring food to the table, while women are expected to give birth to and raise children and prepare food for their husbands and other family members. Sons are expected to get married and have children in an attempt to make sure that their families and clans survive forever, while daughters are expected to help their mothers with family chores and get married, thereby making their families proud and rich (this happens once lobola in the form of cattle, sheep and horses has been paid). Even long after TBI, African families hold onto their expectations and hopes, hence find it difficult that their beloved ones will not be the same (Mbiti, 1969).

As alluded to earlier, an African family includes the departed (dead) relatives, who are now called badimo (ancestors). Badimo are 'alive' in the memories of their surviving families, and are thought to be still interested in the affairs of the family to which they once belonged in their physical life. Surviving members must not forget them, otherwise misfortunes are feared to strike families and their relatives. Those people who died in their older years are still remembered and regarded as an integral part of the human family. Hence they are given offerings of food and libation, which are tokens of fellowship, communion, remembrance, respect and hospitality being extended to the roots of the family. Unlike the ordinary family members, when badimo (ancestors) are offended, it is often said that they take revenge or demand a rectification. It should be noted that even those African families which are nuclear in nature still regard ancestors as an integral part of their family (Mbiti, 1969).

Conclusion

What is clear from this chapter is that brain injury is a family matter. It affects all members of the family system. They may experience anger, guilt and frustration of various degrees. However, in trying to readjust, family members look for different explanations, most of which are coloured among others by cultural beliefs. The next chapter is on the research methodology used in this study.

CHAPTER 4

METHODOLOGY

This chapter contains seven sections. The first section is the reiteration of the aim of this study. It is followed by a section on the research methodology, which motivates why a qualitative research paradigm was used and how its validity is assessed. The following sections deal with the participants and their selection, data gathering techniques and instrumentation, data analysis and research procedure.

4.1. Aims Of The Study

As alluded to earlier, the aim of this research is to give a thick description (Henwood, 1996; Lincoln & Guba, 1985) of the views/perceptions that African families have about TBI and its consequences. It further looks at the implications these perceptions have for rehabilitation and then makes recommendations for drawing up effective rehabilitation programs.

4.2. The Research Methodology

This study was conducted from the qualitative research paradigm. This paradigm was chosen above others because it is more fluid, flexible and responsive to data and more appropriate for the aim of the present study. When discussing the advantages of this research paradigm, Moon, Dillon and Sprenkle (1990, p.359) note that "... qualitative research emphasizes social context, multiple perspectives, complexity, individual differences, circular causality, recursion, and holism. Qualitative methods provide an avenue for examining the experiences from the perspective of the client rather than from the more typical perspective of the therapist and/or researcher".

The case study, ethnography and the phenomenological approach are but three possible approaches within the qualitative paradigm. The phenomenological approach seemed most appropriate for this study because it allows the researcher temporarily to suspend his biases and see through the eye of the co-researchers (participants) and capture their perceptions of TBI. Bogdan and Biklen (cited in Moon et al., 1990, p.358) maintain that "All qualitative research

in some way reflects a phenomenological perspective.” A quotation from Moon et al., (1990, p. 359) will suffice to confirm the epistemological benefits of this method, “Researchers operating in the phenomenological mode attempt to understand the meaning of naturally occurring complex events, actions and interactions in context, from the point of view of the participants involved”. Creswell (1998) concurs with the above quotation when he says that phenomenological approach entails entering the field of perception of participants; seeing how they experience, live and display the phenomenon and finally looking for the meaning of the participants’ experiences. He further cautions researchers making use of this approach that they need not put aside their preconceptions in order to best understand the phenomenon under investigation as experienced by the participants. What he means is that bracketing of personal biases and experiences is difficult to achieve.

The phenomenological approach tries to understand each reality in the multiverse (Gergen, 1991; Hitchcock & Hughes, 1989; Moustakas, 1994; Reason & Rowan, 1981). This approach is based on relativist ontology. It sees reality as multiple: multiple realities are the perceptions of the participants. This research methodology helped the researcher to look for general principles, by examining a handful of cases intensively (Hammersley, 1996; Guba & Lincoln, 1988; Keeney & Ross, 1992; Lincoln & Guba, 1985).

Evaluating the validity of qualitative research has been an issue for a long time. One of the many views is that it is important that qualitative research should be judged against criteria appropriate to that approach. In other words, it should not be evaluated in terms of the canons of validity that have evolved for the assessment of quantitative research, since these have different epistemological priorities and commitments. An enlarged definition of scientific psychology should involve amending the criteria for assessing the validity of different types of research. It is on this basis that authors like Lincoln and Guba (1985) and Smith (1996) among others, have suggested qualitative research validation techniques. Among the prominent ones are, internal coherence, triangulation, member validation, independent audit and the presentation of evidence. In validating this study, the first two techniques were employed (i.e. internal coherence and member validation).

4.2.1 Internal coherence

There is consensus among different researchers that internal coherence (or lack of it) is an appropriate way of assessing qualitative research. Rather than being concerned with the representativeness of the sample used, readers and researchers should concentrate on whether the study was internally consistent and coherent. However, it should be noted that this assessment technique is arbitrary and therefore subjective. The present study has attempted to present a coherent argument as well as deal with loose ends and possible contradictions. It has also taken into account other ways of interpreting data (Hitchcock & Hughes, 1989; Lincoln & Guba, 1985; Smith, 1996).

4.2.2. Member validation/member check

Member validation has dual roots in a phenomenological epistemology and in a commitment to seeking more democratic research practices. It involves taking the analysis of responses back to the participants to enable them to check or comment on the researcher's interpretation. Member validation can be done at a number of possible stages, for example, after some preliminary analysis has been conducted or once a draft report has been written. However, in this study it was conducted after the preliminary report was written (Cresswell, 1998; Hitchcock & Hughes, 1989; Kvale, 1996; Lincoln & Guba, 1985; Smith, 1996). The rationale for doing this, was that from a phenomenological perspective, if a researcher wants to record as closely as possible how a particular individual perceives some situation, it obviously makes sense to check one's interpretations with the participant himself/herself.

Though member validation plays a useful role in qualitative research, it should not be perceived as problem free. However committed the researcher is to the democratic practice, the question of power relations still arises. While the participants may find it easy when they agree with a piece of interpretation, if there is disagreement it may be more difficult for them to question the interpretation of the researcher, who is often perceived as more powerful. This can

also be influenced by the local interpersonal dynamics between the researcher and the participants. Member validation is an attempt to gain fuller understanding of the situation by including multiple viewpoints. Given the right circumstances, it is possible for participants to do much more than just concur with the analysis. Often their interpretation of a text and their response to the researcher's analysis helps to expand the reading that is given (Bless & Higson-Smith, 1995; Lincoln & Guba, 1985; Smith, 1996).

4.3. Participants And Their Selection

In qualitative research, probability sampling techniques are very rare. Instead, criterion based selection techniques are employed to choose participants. Selection means that the researcher delineates the relevant units of analysis precisely by using criteria based on specific considerations before selecting participants and/or phenomena for study, that meet those criteria (Bless & Higson-Smith, 1995; Marshall & Rossman, 1995; Moon et al., 1990).

For the purpose of this study, convenience selection was used. This means that all those meeting the pre-determined criteria were eligible for selection. The study aimed at interviewing 25 pairs of African TBI persons and their caregivers. The TBI 's were three years post-injury and resided with their families in townships and/or rural areas in the Free State Province.

The reason for selecting patients who were three years post-injury is that their recovery process should have stabilised by this time (Lezak, 1995). Therefore, their participation was expected to give valuable information on the TBI phenomenon.

The characteristics of the co-researchers are as follows. There were twenty-four males and twenty females, of ages ranging from sixteen to fifty. Their highest level of education ranged between non-formal schooling to university graduates, while their occupations covered a wide spectrum, for example, labourers, nurses, teachers, administrative clerks, businesspersons and the unemployed. Of the twenty-two pairs interviewed, five reside in the rural areas (namely, farms) while the remaining seventeen pairs reside in the urban/semi-urban areas (namely,

townships and informal settlements). One pair spoke Xhosa, two pairs Setswana, three pairs Zulu and sixteen pairs Sesotho as their home language. Nevertheless, they were all fluent in Sesotho.

4.4. Data Gathering Techniques And Instrumentation

The primary data gathering procedure in the phenomenological approach is the qualitative interview (Lincoln & Guba, 1985; Moon et al., 1990). Kvale (1994, p. 149) defines the qualitative research interview as “an interview, the purpose of which is to gather descriptions of the life world of the interviewee with the intention of interpreting the meaning of the described phenomena”. Qualitative interviews can either be structured, semi-structured or unstructured. However, this distinction is arbitrary. In practice it is the question of both/and, that is, structured, semi-structured and unstructured positions are assumed at specific moments in the course of the interview. In principle and practice, the author was more inclined to use the semi-structured interview. The research posture which was adopted is one which is consistent with ecosystemic epistemology and is one in which both the author and co-researchers interacted as peers, that is, as caring companions with a commitment to empathic search (Massarik, 1981; Moon et al., 1990; Workman, 1996).

The rationale for using the semi-structured interview is that it is a much more flexible version of the structured interview. It tends to be most favoured by most social researchers since it allows depth to be achieved by providing the opportunity on the part of the interviewer to probe and expand the interviewee's responses. This can also be done by including spaces on the interview schedule for the interviewer to add or make notes. In this way some kind of balance between the interviewer and the interviewee can develop, which can provide room for negotiation, discussion and expansion of the interviewee's responses (Hitchcock & Hughes, 1989).

Pidgeon and Henwood (1996, p. 89) view semi-structured interviews as a “directed conversation” and not as a closely controlled, monitored and measured pseudo-experiment. In order to obtain standardised and structured responses from all co-researchers without alienating them by breaking the flow of our conversation, the following areas were covered:

A) Cognitive problems

- ◆ Memory -both auditory and visual
- ◆ Attention
- ◆ Planning ability
- ◆ *Receptive language*
- ◆ Inability to follow instructions
- ◆ *Expressive language*
- ◆ Aphasia
- ◆ Tangential speech
- ◆ Talkativeness
- ◆ Slow speech
- B) *Sensori-motor problem*
- ◆ Motor coordination - both fine and gross
- ◆ Dysarthria
- C) *Emotional problems*
- ◆ Self-esteem
- ◆ Dyscontrol
- ◆ Sexual dysfunctions
- D) *Psychiatric problems*
- ◆ Depression
- ◆ Anxiety
- E) *Social problem*
- ◆ Interpersonal skills
- ◆ Work impairment
- F) *Socio-cultural factors/attributes*
- ◆ Perception of TBI -experience and understanding
- ◆ Effects of TBI on family functioning

The first five areas, namely, cognitive, sensorimotor, emotional, psychiatric and social problems formed a framework within which socio-cultural attributions of TBI were explored. It should be reiterated that , though questions were phrased (worded) differently when conversing with different co-researchers, being influenced by among others, their level of

sophistication and/or education, a deliberate attempt was made to address the same themes (aide-memoire). This is in line with Pidgeon and Henwood's (1996) epistemology, that interviews are not monitored and measured pseudo-experiments but directed conversations. All co-researchers' responses were recorded on record cards for later, thorough analysis.

The aide-memoire (check list) above was adhered to because all TBI 's are known to have problems in these areas. So, by addressing these areas the researcher wanted to confirm that patients were indeed TBI 's of various degrees, ranging from mild to vegetative state (Lezak, 1995).

4.6. Data Analysis

According to Lincoln and Guba (1985) and Moon et al., (1990) data analysis in qualitative research is inductive, recursive and messy. It occurs throughout the data collection phase of the research rather than at the end. Inductive data analysis which is employed in this study, may simply be defined as a process of making sense of the gathered data, the purpose of which is not to support a hypothesis but to generate rich descriptions of the phenomenon under investigation. The multiple realities of each participant are embedded in these descriptions. Inductive data analysis in this study entailed looking at patterns of meaning in the data gathered through interviews (thematic categorisation) (Lincoln & Guba, 1985; Marshall & Rossman, 1995; Moon et al., 1990; Moustakas, 1994). Thematic categorisation was arrived at by engaging in the following processes:

4.6.1. Familiarity with the responses

It is important for the researcher to have a thorough familiarity with the interviews or conversational material in order to develop a kind of systematic analysis. The processes of reading and re-reading the materials (recorded responses/collected data) enabled a sense of their coherence as a whole (Hitchcock & Hughes, 1989; Lincoln & Guba, 1985).

4.6.2 Appreciation of time-limit

A fair amount of time was spent on reading and re-reading interview/conversational materials. This presented the researcher with an important practical matter to solve. Given the restraints facing the researcher, it was better to analyse a relatively few interviews (22 pairs) well, than a large number badly (Hitchcock & Hughes, 1989; Lincoln & Guba, 1985; Marshall & Rossman, 1995).

6.2.3 Description and analysis

The researcher moved backwards and forwards between description and explanation. In effect, this means developing what Glaser and Strauss (cited in Hitchcock & Hughes, 1989) call “Grounded Theory”. According to Hitchcock and Hughes (1989, p.98) “ By grounded theory is meant the production of analysis and explanation which is grounded in the data the researcher collects, since it requires the researcher to move consciously backwards and forwards between the data and the emerging explanations, analysis and eventually theory”. The researcher continually moved around amidst the raw data contained in the field notes/ transcripts and accounts and then back to analyse, synthesize, and formulate what has been found. This process allowed the researcher to move back and forth, between data and description for further evidence, examples and clarification thereby generating and/or adding to the existing theory on TBI in non-western communities.

4.6.4 Isolating general units of meaning

The researcher was in a position to consider very general units of meaning, that is , the broad themes and issues which recurred frequently in the interviews. The general units of meaning refer to the range of issues co-researchers referred to and these in turn were related to the overall focus of the research. The researcher identified, extracted and commented on the general units of meaning (Hitchcock & Hughes, 1989).

4.6.5 Relating general units of meaning to the research focus

Once the researcher has isolated the general units from the interviews, they can be examined in relation to the research focus, topics and concerns. It is important to note that the materials themselves are placed against the research focus and not the other way round, which might lead to forcing the materials into the researcher's prearranged ideas and hypothesis. This would run counter to the general ethos of "grounded theory". Since, by definition, unstructured and semi-structured interviews/conversations are fluid, the scope for straying from the relevant issues to other "relevant" issues is quite large. Whatever the case, the researcher is likely to find that there is much in the so diligently collected data which bears very little relation to the task at hand. The extracting of general units of meaning which relate directly to the focus of the research, involved leaving much data out (Hitchcock & Hughes, 1989).

4.6.6 Patterns and themes extracted

This is the point at which the researcher can explore in greater depth the major themes which emerge from the data and the ways in which these relate to the focus of the research. There is almost a limitless number of topics the researcher might explore. The constraints will surround the time the researcher has to explore these topics and the ways in which s/he intends to explore them. Most of the issues the researcher chooses to focus upon come from the immediate cultural and neighbourhood context. Hence the patterns and themes extracted from the interviews/conversations might be seen in relation to this (Hitchcock & Hughes, 1989; Lincoln & Guba, 1985).

It is anticipated that the patterns and themes extracted, and the kind of analysis made of the interview/conversational material will throw some light upon the perceptions African families have about TBI and its consequences

4.7. The Research Procedure/ Process

This section has five subsections. Its purpose is to explain step by step the procedures engaged in during the course of this research.

4.7.1 First and subsequent contacts

A central ingredient in the successful completion of phenomenological research is the establishment of good and effective relations. This involves the development of a sense of rapport between the researcher and co-researchers, which lead to the feelings of trust and confidence. Inevitably, the researcher receives much information on trust from co-researchers. As a result, the researcher has to develop some way of safeguarding their anonymity by, for example, the use of pseudonyms and changing some details which might betray their identity (Hitchcock & Hughes, 1989). The co-researchers were given an assurance that no identifying details would be used, even in future publications that may emanate from this study.

During this very first session the researcher explained as clearly as possible the aim and methods of this study. Each co-researcher was allowed the right to refuse to take part in this research. If one of the two co-researchers, that is, either the patient or the caregiver refused to participate, both of them were removed from the sample. However, it should be understood that the caregiver's consent held more water than the patient's, because some of them (patients) were so incapacitated and lacked insight. After both parties had given their consent, most importantly the caregiver, interviews were scheduled for three weeks later. Even after the interviews were scheduled, co-researchers still had the right to change their minds.

Subsequent contacts were made when further clarification and views were needed, especially relating to perceptions families have about TBI and the recommendations for rehabilitation.

4.7.2 Language issue

Of the twenty-two (22) pairs of co-researchers, sixteen (16) pairs spoke Sesotho, one (1) pair Xhosa, two (2) pairs Setswana, and three (3) pairs Zulu, as their home language. However, it should be noted that since all co-researchers have stayed in the Free State for more than ten years, their Sesotho was fluent. As a way of standardising the interviews, they were conducted in Sesotho. Nevertheless, where some ideas or concepts needed elucidation, their home languages were used, since the researcher is fluent in all of them. It is acknowledged that the latter procedure may have constituted a source of bias, though it was kept to its minimum.

The procedure discussed above was engaged in as an attempt to address the problem identified by Hitchcock and Hughes (1989, p.93) when they say "By describing the interview as a 'speech event' we are drawing attention to the communicational and socio-linguistic aspects of its organization and the production of data contained within the interview and conversational materials in terms of what it is that the parties are doing with words, phrases and idioms that they are using". Most issues become more apparent when the interviewer and interviewees use different linguistic styles or dialects within the interview or conversational encounter. Voluminous studies on research in multicultural contexts point to the potential for misunderstanding and miscommunication when the researcher and co-researchers are from vastly differing cultural backgrounds having different languages and speech styles. It should be noted that the language of the researcher and the co-researchers is closely aligned to their definition of themselves, the encounter and the front, image or presentation of self they wish to convey (Hitchcock & Hughes, 1989).

4.7.3 Place of interview

Though the study aimed at interviewing patients and caregivers in the whole Free State, due to financial constraints it finally focussed on the eastern Free State, particularly, Bethlehem, Kestell, Harrismith, QwaQwa and the surrounding informal settlements. The interviews were

conducted at each co-researcher's home. The purpose was to make them feel at ease. Where possible, patients were interviewed separately from their caregivers, in an attempt to avoid a situation where they would influence each other's responses.

4.7.4 Reason for refusal

A total of 27 pairs of patients and their caregivers were approached, of whom twenty-two (22) pairs participated in the study while another five (5) pairs refused to participate. The reason given was they believed that if they discussed the TBI with a stranger, patients would not recover fully. It would have been easier talking to the researcher if he was not a complete stranger (i.e he was a doctor in a medical setting). Their response is linked to a cultural practice and belief that after sustaining an injury, one ought not show the wound to strangers lest the wound become septic and take very long to heal, if at all. This is based on one of the aspects of African oral traditions (Mbiti, 1969).

4.7.5 Validation

According to Hitchcock and Hughes (1989), the researcher should go back to the co-researchers with a complete transcript or a summary of the main themes and emerging categories in an attempt to check or validate the interview material (data). One of the many aims of doing so is to re-interview the individuals concerned (that is, those from whom further clarification is needed) and become engaged in subsequent re-analysis. For the purpose of this study, a summary of the main themes and emerging categories was taken back to co-researchers for comments, while some were re-interviewed. All of these courses of action offered the co-researchers the opportunity of adding further information, and the researcher the opportunity of checking on what data had been collected. Re-interviewing was used to focus upon themes and issues which emerged during analysis, and those on which the researcher was not clear.

These are the ways the researcher tried to check and validate the data. According to Hitchcock and Hughes (1989, p.106) "One cannot, however, rule out the possibility of intentional errors.

As we have noted ... the first task in establishing the accuracy of accounts in the field is to place them in their ethnographic context and consider whether or not they hold up under scrutiny”

For those co-researchers whose level of education was low and who did not understand English, vernacular interpretation of the report was provided.

Conclusion

The data collection and analysis were undertaken in such a way that perceptions of the co-researchers, and not of the researcher were relatively accurately captured. The following chapter is the discussion of the findings/results of this study.

♦♦

CHAPTER 5

FINDINGS

It is appropriate to reiterate the aim of this study in order to put the reader in the picture. The aim of this study is twofold. Firstly, it is to give a thick description (Henwood, 1996; Lincoln & Guba, 1985) of the views/ perceptions that African families have about TBI and relate them to the existing theory; secondly, to discuss the implications these perceptions have for rehabilitation and then make recommendations for effective programs.

During the data collection phase of this research, inductive data analysis and thematic categorisation were engaged in. In this chapter, the themes that emerged during analysis are discussed. These themes are classified into four categories, namely, families' perceptions of how TBI has changed the patients, families' perceptions of TBI and its consequences, and perceptions of how the consequences of TBI have affected family functioning, both negatively and positively.

The first category of themes are areas of functioning that are known to be vulnerable to TBI, while categories of subsequent themes emerged when reading and re-reading the transcripts.

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5.1. African Families' Perceptions Of How Patients Have Changed As a Result Of TBI

As alluded to earlier, five areas/ spheres of functioning that are known to be vulnerable to TBI were explored with some patients and all caregivers. The five areas are cognitive, motor, emotional, psychiatric and social functioning (Bond, 1984; Brooks, 1984; Levin et al., 1982; Lezak, 1997).

5.1.1 Cognitive functioning

A significant number (20) of caregivers indicated that their charges were having problems in the area of cognitive functioning. The patients' memory, that is, both visual and verbal, was poor. One caregiver said "If we send him to the shop, he forgets what he was supposed to buy... More often he even forgets that he was running an errand". Most patients had to be constantly reminded to do things. A patient said (with a broad smile) "I have this strange sickness of forgetting everything all the time"

Because paying attention is a prerequisite for memory, it is not unusual to also have problem with attention and concentration. Information gets stored in memory because it was attended to, otherwise it gets lost (Brooks, 1984; Kinsella, 1998; Lezak, 1995; Watson, Horn, Wilson, Shiel & McLellan, 1997). Seventeen caregivers indicated that their charges were unable to attend to and concentrate on a task or conversation for roughly more than three minutes. A caregiver said "It is surprising how quickly bored he gets. This has been noticeable since the accident" Seven pairs of patients and caregivers endorsed this statement.

Planning their daily activities and keeping to a budget, was also problematic for most patients. Caregivers had to become managers. One caregiver said "He smokes a lot. As a result, if you give him money, no matter how much, he will buy as many boxes of cigarette as possible, thereafter come and tell you that he would like to buy some sweets but he does not have money..."

One patient said "In the morning I bask in the sun, have a nap after lunch and look forward to sleeping at night... Yes, this what I do daily." This statement shows lack of initiative, which is commonly reported among TBI's (Lezak, 1997).

Two patients could not follow verbal instructions because they were in a vegetative state.

Ten found it extremely difficult to follow instructions, while seven found it relatively easy and the remaining three followed instructions with ease. The two patients who could not follow verbal instructions were also aphasic. Seventeen were tangential and talkative. One caregiver said “ If you ask him a question, he will not answer it, instead he will talk for a long time, confusing you. There is no coherence in what he says... At times this kind of behaviour makes me angry”. The remaining three patients’ expressive language was characterised by a slow speech. A caregiver said “ Her speech is so monotonous ... She takes very long to utter just one simple sentence.” Talking to these patients needs patience and considerable effort. As a result they are isolated and lonely.

The above observations correspond to the well documented cognitive effects of TBI, such as problems in maintaining attention, processing complex information, storage and retrieval of information, problem solving, inability to use conceptual and abstract thinking and a general slowing of performance in all spheres (Brooks, 1984; Kinsella, 1998; Rosenthal, 1984; Tate, 1998).

On the work and academic/study fronts, fifteen were unemployed while seven have gone back to work and/or studies. Of the seven patients, five were not coping at all due to cognitive impairments they sustained. These findings are consonant with other researchers findings which indicated that most patients are incapacitated to a larger extent by cognitive deficits than any other kind of deficit (Lezak, 1995; Orto & Power, 1994; Tyerman, 1996).

5.1.2 Motor functioning.

The motor coordination (both fine and gross) of all patients was impaired. Ten of the patients found it extremely difficult to maintain balance on one foot or walk in a straight line and to write on a piece of paper in a straight line. Seven of the patients have a condition known as dysarthria (this is a defective articulation characterised by imprecise articulation, distorted vowels and monoloudness) (Lezak, 1997) which all caregivers did not understand.

One caregiver said “ There is something disturbing about him... At times he produces sound as if he wants to talk and face muscles twitch, but when you enquire he just looks at you, puzzled.”

5.1.3. Emotional functioning and personality

TBI is known to change the emotional functioning and affect personality traits of patients. Some of the patients who were calm and well adjusted prior to the injury became irritable, aggressive and abusive. One caregiver said “ You can not tell him how to do things appropriately. Once you try, he becomes irritable and verbally abusive. However, he was not like this prior to the injury.” Four of the patients have blunted affect. One caregiver said “ Whenever I look him in the face , I wonder why he looks like a zombie. He does not look angry, happy or show any known facial and emotional expression. He just looks blank”

On the other hand, some patients who were known to be very aggressive, abusive and assaultive prior to the injury have become subdued. Their self-concept has also changed. Rather than seeing themselves as beasts, they now regard themselves as sociable and caring people who are liked and accepted by their community. However, there are those whose self-concept has been negatively affected, because they can no longer do what they used to do prior to the injury.

Some patients and their caregivers did not have insight into their emotional and personality changes. When asked about changes in these areas they looked puzzled. However, some acknowledged that changes have taken place but struggled to pin point the affected areas. It is clear from the above observations that patients manifested commonly cited emotional and behavioural consequences such as lack of insight, blunted affect and aggression to mention a few (Lezak, 1997; Rosenthal, 1984; Wood, 1984).

5.1.4 Psychiatric functioning.

The majority (15) of caregivers reported that their charges showed signs of depression, for example lack of initiation and neglected hygiene. Two of these patients attempted suicide. The depression is pervasive and affects other people around them. More often it affected both patients and their caregivers. A caregiver said “As much as he has a depressed mood, so am I, maybe worse than him”

5.1.5. Social functioning

As alluded to earlier, some patients who were difficult prior to the injury became sociable and easy-going after the injury, and vice versa. However, three patients did not agree with their caregivers that they have changed in terms of how they relate with other people, that is, they showed lack of insight into their behaviour (Johnson, 1998; Rosenthal, 1984).

One of the patients who lead a lonely and isolated life prior to the injury said “I think I have changed. Prior to the injury I did not have steady friends. Most of the time I was alone, either listening to music or reading magazines...Since the injury, I like to be with people. To tell you the truth, I find it easy to befriend them...”

..

One of the patients who was highly promiscuous prior to the injury was described by his caregiver as a “...my sweetheart, who does not care about women anymore”. However, the strangest thing is that he now likes to associate with little children. In effect, his friends are pre-school children who stay next door. Is that normal?”. This patient was disinhibited. More often, disinhibition is a consequence of a damage to frontal lobe structures, which results in blunting of various social skills and a tendency towards inappropriate behaviours (Lezak, 1995; Rosenthal, 1984; Wood, 1984).

5.2 African Families' Perceptions Of TBI And Its Consequences.

Families' responses to questions regarding the nature of TBI and possible causative factors could be categorised according to six main themes, namely, witchcraft, ancestral anger, God's wish and mercy, thwasa, accident and Satanism.

5.2.1. *Witchcraft*

Of the twenty-two pairs of patients and caregivers, nine believed that the accident that led to TBI and its consequences was due to witchcraft. Reasons advanced for bewitchment are, among others, jealous neighbours who wanted them to divorce or who wanted their child not to prosper and achieve academically and career wise. One mother said "If it was not witchcraft, how is it that five years after the injury my son appears mad, mind you, before this injury he was a genius at the university. What you see here is a product of witchcraft".

Getting married to another woman other than the witch's daughter was also cited the reason for the accident. The patient's mother said, "My son jilted her daughter, after which she came to enquire the reasons. Hardly three years passed, and my son paid lobola for his new fiancée. Then he was told over the phone by his former girlfriend's mother "O tla se bona (Do not expect anything good)". Normally, the latter expression is made to indicate that the speaker is angry and will resort to witchcraft to settle the differences s/he has with others.

The wife of a taxi owner who is confined to a wheelchair said "They bewitched him because they wanted to see me and my children suffer.... I was always accused of being boastful since I am married to a successful businessman".

Even patients themselves believe that they have been bewitched. One of them said "I became like this after picking a fight with one guy, and not so long thereafter I was involved

in an accident that left me this way... I mean, mad and disabled as this". He suspects that witchcraft is the link between these two incidents, that is, the fight and the accident/injury that left him incapacitated.

5.2.2. *Ancestral anger*

It is believed that ancestors became angry for various reasons that left some patients affected for life. Five pairs of co-researchers adhered to this explanation. However, others (two pairs of co-researchers) believed that if some traditional rites and rituals could be performed, the consequences of TBI would disappear. Reasons for ancestors' anger included getting married to someone the ancestors do not approve of, for various reasons, like s/he is your relative in some way (sharing the same surname), refusing to go to the initiation school (lebollo) and changing churches (that is, moving from the orthodox to evangelist churches). The belief is that if things are done appropriately, that is, in a culturally appropriate manner, the effects (consequences) of TBI will be reversed or ameliorated. For example, to pacify the ancestors, it is appropriate to make offerings (Phabadimo), after which family matters including illnesses become better.

People who believed that witchcraft and ancestral anger played a role in TBI and its consequences consulted traditional healers (Isangomas, inyangas and diviners) for their problems. Five pairs of co-researchers reported that the symptoms were becoming better and more manageable when using muti (medicines given by traditional healers).

5.2.3. *God's wish and purpose/mercy*

One pair of co-researchers and two caregivers perceived TBI and its consequences as a consequence of God's wish and purpose/mercy. However, two patients themselves disagreed, saying it is the result of witchcraft. One of them captured it beautifully when she

said, "God has a definite purpose for everything, and every incident including accidents and injuries." Two of these caregivers said the injuries happened because God wanted to tell the patients to repent from their wicked ways. One of the patients was a gangster while the other one was "... just an irresponsible person, who, on month end did not care about his parents and siblings, though everybody looked up at him to put food on the table". The caregivers believed that God's purpose and mission have been accomplished because since the injuries/accidents patients have repented, though they are both jobless.

One caregiver was not sure how to describe his perception of TBI and its consequences. He said "I am always confused. At one moment I think that what I see in front of me, in my house, is God's wish and purpose. Then the second moment is, *Ha se nnete taba ena, baloi ba mpitsitse* (No ways, they have bewitched my family). How can God allow them to put my family through this devastating experience". The patient concerned here could not give responses because he is completely dependent and severely impaired. He was bedridden and could not even speak.

All caregivers except the last one, relied on their faith and the support of other congregants for their daily coping. They believed that they have to be strong in their faith "...during these trying times lest Satan have a chance of destroying us and our families". Two caregivers related the story of Job, to support their case. One of them said "Do you remember what happened to Job? God had given permission to Satan to try to win Job to his side. And God knew that Job had faith in Him. Job lost everything, I mean including his sons and daughters. Yet he remained loyal to God. It was the fiercest test of his faith and he was never derailed. So should we be". So, TBI and its consequences are understood as God's way of testing the family's faith in Him.

The caregiver that is confused, that is, the one who does not know exactly whether TBI is God's test of the family's faith or witchcraft, relied on his faith in God and traditional healers for daily coping. He said, "My upbringing as an African dictates that in times of

troubles like this, I should consult ancestors' messengers (traditional healers). On the other hand, due to western civilization, particularly Christianity that has touched me in some way, I also feel compelled to look for support among fellow Christians, which in a way is ubuntu".

He continued to say "What confuses me more, is that when I tell some of these fellow Christians that I have been to some traditional healers, they rebuke me, yet some of them are known to be regulars at traditional healers' rooms".

5.2.4. *Thwasa*

Three pairs of co-researchers perceived TBI and its consequence to be due to thwasa. They believed that if the patients can go through this rite of thwasa they would be fine again. One of them said, "If you are called to join the ranks of the messengers, you definitely have to be different. And ancestors make you different by touching you, either through minor ailments or incidents, like an injury. And while in hospital or at home, feeling sort of being between life and death (unconscious), then one ancestor who was him/herself a sangoma or nyanga gives you directives that should be carried out as soon as you return to normal life."

According to some co-researchers one recovers fully after one has carried out all ancestors' directives. "Normalcy here, does not mean the same status as before the injury, because you have to be different from people who have not been called by the ancestors. That difference is what I call normalcy".

For those who do not carry out the directives, punishment is meted out by the responsible ancestor (that is, the one whose proposal was rejected) and at times any other ancestor. This punishment takes the form of madness and/or epilepsy or not recovering at all from the consequences of TBI.

The directives given during the “between life and death” stage, that is , while still unconscious are, the name and the place of the mosuwe (teacher), kinds of beads to wear, the colour of the cow and/or sheep/goat to be slaughtered at the completion of the initiation rite (lefehlello).

Co-researchers in this category relied on traditional healers for their daily coping. Normally these traditional healers are appointed by the ancestors and introduced during the “between- life- and- death” stage. Nevertheless, one caregiver and patient indicated that they also rely on their church congregants for support. The caregiver said, “Things have drastically changed these days. In the past, one would not be allowed to attend church if one or one’s family member was in the process of thwasa. These days every congregant gives support. This is the position only in the orthodox churches. In the evangelist churches, thwasa is seen as demon possession. Therefore, thwasa is not allowed and accommodated in the evangelist churches.”

5.2.5. *An accident*

One caregiver and patient pair described their perception of TBI as “....a mere accident that could have happened to anybody”. They perceived the consequences of TBI as the aftermath of a terrible accident. The caregiver said, “After a turbulent storm, many things are discovered to have been negatively affected, for example, foundations of some houses sink while other do not, others leak thereafter. In short, there are things you can prevent and avoid, but others are difficult. So some of the consequences of the terrible injury are being looked after by the medical practitioners and psychologists while we have to adjust to some”. The patient agreed with the caregiver. He said “ This was a mere accident. I was at the wrong place at the wrong time. It could have happened to anybody who was at that time walking at that spot”

Concerning the consequences he said, “You cannot expect me to be OK, I mean normal

when I have had a near death experience. I was dead for almost thirty-five days, it is just another accident that I am still alive". He said that though he regards whatever happened and his survival as an accident, he at times, "...regards it as God's glory and mercy, not forgetting my ancestors". As to whose support they rely on at this trying time, they said they are at God's and ancestors' mercy.

5.2.6. Satanism

One caregiver said that TBI and its consequences are products of Satanism. He said, "When we received a call that she was in hospital after being injured in a motor vehicle accident, we thought she was seriously injured. When we arrived at the hospital she was in the ICU(intensive care unit) but had no visible injuries. It was a devastating experience....The information we gathered later was that the taxi she boarded on the day of the accident, was also boarded by one follower of Satanism. Some occupants overheard her (the follower) saying, "At least there are more males than females in this taxi. I will give my master fresh male blood as sacrifice. As for the ladies, I curse them for now. They are not always cooperative".

On the basis of this story (the rumour) she understands the odd behaviour of her daughter as a curse from Satan. Before this accident, the caregiver who is also a single mother was not a staunch Christian, but since the injury she is a staunch believer/Christian, "...because the only way to defeat Satan, is to stick to Jesus' cross".

On the other hand, the patient did not agree with her. She said, with a broad smile, "After the death of my father, people, including our relatives were accusing us of all sorts of things. They went to the extent of trying to rob us of whatever we inherited as his heirs. We put up a strong fight and we won. However, when I went to the university they started again. You can imagine what would these people do, when I finished my degree. They were bitter. So, you get what I mean. They bewitched me. And my mother does not want me to say so."

While the caregivers' perception is that Satanism has contributed, the patient thinks it is witchcraft. The patient said "I did not hear anybody saying this story in the taxi I boarded. After all I do not believe that Satanism exists."

5.3 Perceptions Of How The Consequences Of TBI Have Affected Family Functioning.

This section is divided into two sub-sections, namely, negative and positive aspects resulting from the consequences of TBI.

5.3.1. Negative aspects

As alluded to previously, brain injury is a family matter, that is, when it occurs it affects the whole family functioning. Each family is unique in all respects, therefore each responds to TBI differently. The following is a discussion on how family functioning of the respondents (co-researchers) was affected.

5.3.1.1. Confinement to the house and embarrassment

The families are no longer as free as they were before the injury. For the four pairs of co-researchers, of whom two patients were severely impaired and are in a persistent vegetative state, somebody always remains with the patients. One caregiver said, "... it is so difficult for all of us to attend a funeral or any feast at the same time. At least one of us should remain at home and look after the patient".

In effect, families experience a catch 22 situation. They are stressed if they go out leaving the patient alone, and they get embarrassed when other people visit them. One of the caregivers said, "Though it is difficult for us to go out, it is equally embarrassing to host guests. Our child behaves in an unbecoming manner in front of guests and everybody. For example, he likes masturbating and telling guests that they have overstayed their welcome.

He is so aggressive...”.

However, for other families, everything seemed to be under control and acceptable, as shown by one caregiver who said “ We have accepted his condition, that he is irritable, aggressive and can not concentrate for a relatively long time. We always console ourselves by acknowledging that there is no African family without a disabled person”.

5.3.1.2. Financial struggle

For those families whose breadwinner or money earner sustained TBI, financial problems were encountered. One caregiver said, “ We are really struggling, I mean financially. We used to get over ten thousand a month, but since the injury, I have to pay our helper. I really feel the pinch. The sum of money we received from the insurance is being spent on medical care. It is really difficult”.

The patient who was medically boarded after the injury said, “ My family has paid so much, we are even using the reserves. This simply means we are struggling. And as a result of this struggle, my wife has divorced me. My sons are my only hope. At least I do not struggle with them, and that gives me pride”.

..

A single mother said, “ The financial struggle is unbearable but I hope God will hear my prayer”. For those families with completely dependent patients the financial struggle is even worse. The families are unable to give the necessary medical care to the patients. One member of such a family said, “We struggle, and at times I ask God to take the soul of the patient. In effect, if euthanasia was legal in this country, we would have long sought it. We have been to many places trying to get help but to no success. I really feel down and out”.

5.3.1.3. Planning around the patient

There is little if anything that is planned in the family that does not take the patient into account. One caregiver said, "Unlike with other family members, we plan our movements and commitments with her as the centre. Even when we have to attend a funeral or traditional feast (Phabadimo), we have to plan in advance and to make arrangements that would cater for her. So she is very influential in the planning of this family, so to speak".

A sibling of one of the patients said, "Even when I plan my marriage, I have to find a place to fit him in. You see, our parents are old and will die soon. If they die before him (the patient) we will have to take him into our home. That is ubuntu. But how many women can tolerate that."

5.3.1.4. Change in the sleeping arrangement.

The injury of the severely impaired patients has drastically affected the family sleeping arrangements. One couple share a bedroom with their impaired son. The reason is that "... we cannot afford to leave him alone in his room. Sometimes when he wakes up, he is confused and he needs somebody to assure him that things will soon be fine. What prompted us sharing a room with him is that he once woke up and started breaking everything in his room. So we share so that we will be able to stop him."

For another family, not only the sleeping arrangement has changed, but so has the sleeping pattern. When some members are asleep others are awake. One member said, "We are never all asleep at the same time. We try to keep the light burning throughout the night. However, some relatives have accused us of being hyper-vigilant for no apparent reason."

Even family members who do not stay in the same place as the patient showed concern. A caregiver said, "Her brother is so concerned. I wonder when does he sleep. For the last

three years, he has been phoning at least three times a night just to check on everybody and to boost our morale.”

5.3.1.5. Negative self-concept

Self-esteem of some patients has been negatively affected. Those who sustained the injury while still working and looking after themselves have depressed moods. One who was a teacher at the time of the injury said, “Since medically boarded, I feel worthless. This has been aggravated by our divorce. Just to show how worthless I am, my wife of more than fifteen years divorced me”.

He further said, “The more I think of our divorce, the more I feel worthless and the more depressed I feel. Do you think you would feel OK when you are unable to provide for your children, never”.

A graduate who sustained injury before securing a job said, “I have a degree, but why did I do it? I have realised that I will not cope in the work situation. I am labile and my concentration is very poor. My degree is useless, and so am I. I always wish I could sell it (the degree) and be able to buy back all I have lost due to the injury.”

When talking about her social life she said, “I have lost my boyfriend, (started crying) a very caring and loving sweetheart. Why? Why? Is it not that he realised how useless I was and still am? I guess that is the only reason why he left me alone.”

Patients who do not have insight into their impairment do not worry about their changed functioning. One of them said, “Even though I do not work I do not care .”

As alluded to earlier, TBI is a family matter. Therefore, it does not only affect the self-esteem of patients but also that of other family members. One caregiver captured it well by

saying “ We feel ashamed as a family because we are unable to attend community gatherings like phabadimo and funerals. We are not doing anything constructive for our community. Things took this shape after his injury... However, some community members empathise and sympathise with us while others thinks we are arrogant...”

5.3.2. Positive aspects.

Though TBI and its consequences are often incapacitating, there may be certain positive aspects which are discussed next.

5.3.2.1. Family cohesion and mutual caring

In some instances TBI and its consequences have brought about greater family cohesion. The sentiment expressed by one caregiver encapsulates this, “I would not say that we were a true family before the accident. Each cared more about him/herself. Since the injury, we have come closer to each other, share more of each other’s feelings, thoughts and respect each other more. Though the injury has saddened us, it has given us peace and more love.”

One single mother commented that “I was devastated at first. But after long hours of introspection, I came to realise that the injury has robbed me of my son⁴, who was very aggressive, liked experimenting with all sorts of things and behaviours, and has in turn given me one of my dearest dreams, *an only daughter*. He has changed to be a very cooperative and caring person. And our relationship has since positively changed .”

The teacher, whose wife divorced him said, “God is a loving father. He always takes something only to replace it with something more precious. She divorced me and left me with my two sons. My relationship, especially with the eldest is so good, you might think that we are brothers. We are always there for each other. Something that never happened before the injury ”.

A patient expressing the sentiment of cohesion and mutual sharing said, "The injury has made me realise the extent to which my folks care about me. Before the injury, I had thought that my parents and my brothers did not care a bit about me, but now I know the truth. They are with me every step of my life."

5.3.2.2. Boosting of self-esteem of caregivers.

Though the injury might negatively impact on the patients' self-esteem, for some caregivers it is different. The single parent who struggled financially said, "As a single mother, whose husband died fifteen years ago, I feel proud. Though I struggle financially because I do not hold a good paying job, but I always make ends meet. I am proud to be one of the single parents defying the odds. I always feel good about my family and myself. And I know that my dead husband would not like to see me succumbing to life's hardships. Thanks to him."

5.3.2.3. Financial support/gain

Although the injury made some patients burdens, it made others saviours of their families. Churches and other non-governmental organizations give financial support in the form of food packages to patients and their families. One caregiver said, "At first, we were devastated by the injury. Later on, we realised that it was a blessing. Nobody works in this house, but because he (the patient) gets food package from the organisation and some from our church we are able to survive."

The son of the teacher who got medically boarded said " Since my father was medically boarded, we enjoy life much better. He affords to buy us whatever we want. He got some thousand rands from his employer and the insurances (accident ones). And though more of that was spent on medical care he has at least stabilised and that has given us a chance to enjoy some of the thousands. After all, he keeps reminding us that it is better for a parent to

die instead of his children (Marabe o jewa ke bana).”

5.3.2.4. Coming closer to God/Repentance

A handful of patients and caregivers confessed that they were not staunch Christians. However since the injury they have moved closer to God. One said, “The injury was God’s message of saying, “you have come to the end of times, so come to me and feel safe”. And we did exactly that. We go to church every Sunday and our congregants are very supportive. An indication that God cannot forsake his children.”

One of the patients said, “I think I have repented. I used to be very aggressive, stubborn and everything bad. However since the injury I have not fought anybody nor offended any. Doesn’t that show that I am God’s newly born child? And everyday my mother reminds me to pray to God and thank him for having saved my life. I do that straight-away.”

Conclusion

As indicated in the methodology chapter, data analyses of this study was messy and recursive, that is, it entailed reading and re-reading the field notes, going back to the co-researchers with the themes that emerged after thematic categorisation in order to confirm/disconfirm the interpretation made by the researcher and to seek clarification where it was needed. The results presented here are the product of all these processes.

In summary, some patients and their caregivers noticed changes in cognitive, motor, emotional and personality, psychiatric and social functioning, while others did not due to lack of insight. The possible causative factors identified are witchcraft, ancestral anger, God’s wish and mercy, thwasa, accident and Satanism. Lastly, both positive and negative

consequences of TBI on the family system were highlighted.

It has been observed that co-researchers in this study did not believe in chance. They believed that accidents, injuries and mental disorders among others occur with a specific intention and that the causes thereof can always be identified (Buhrman, 1986; De Velliers, 1985; Hammond-Tooke, 1975). Their perceptions of TBI can therefore be categorised under what the Zulus and Xhosas call, *ukafa kwabantu*, that is, disorders caused by supernatural factors. Under this category are incidents and disorders caused by God, the ancestors and magic (witchcraft) to mention a few (Fernando, 1991; Swartz, 1986). However, their understanding of why the injuries/accident happened does not take away TBI and its ramifications. No matter the explanation, it remains. The next chapter discusses the findings of this study and makes recommendations on how best the needs of the patients and their families can be addressed.

CHAPTER 6

DISCUSSION

As alluded to earlier, the aim of this study is twofold. Firstly, it is to give a thick description (Henwood, 1996; Lincoln & Guba, 1985) of the views/perceptions that African families have about TBI and relate them to the existing theory; secondly, to discuss the implications these perceptions have for rehabilitation. This chapter is therefore presented within the framework of these aims. The findings, interpretations and recommendations were subjected to member checks (member validation), which is a procedure where the researcher solicits participants' views of the credibility of finding and interpretations (Cresswell, 1998; Kvale, 1996; Lincoln & Guba, 1985). This procedure involved taking themes, conclusions and recommendations back to all participants so that they could judge the accuracy and the credibility of the presented account. What Stake (cited in Cresswell, 1998, p.203) calls "critical observations or interpretations" are given below. In this chapter the author takes a meta-position in examining the role he played in this research, examines the limitations of the study and suggests possible follow up studies. The study is concluded by summarising the main points.

6.1. Families' Experience Of TBI

The findings of this study regarding the impact of TBI on the family system are congruent with the consequences of TBI documented in the literature (Hubert, 1985; Koscuilek, 1997; Tyerman, 1996). It was found that most care givers noticed impairment in their charges ranging from mild to severe, particularly in the five areas/spheres of functioning that are known to be vulnerable to TBI, namely, cognitive, emotional/personality, psychiatric, motor and social areas (Martin, 1990; Orto & Power, 1994).

These findings for African families are consistent with other researchers' findings elsewhere in the world, for example, Hubert (1985), Lezak (1995), Orto and Power (1994) and Tyerman (1996) to mention a few. They confirmed that the needs for care and assistance of brain injured

individuals and the cost of meeting such needs are substantial. As a result brain injuries affect not only the patients, but also their families. As it emerged from this and other studies, ongoing difficulties that families encountered included emotional, personality, physical and behavioral changes, lack of information about TBI and appropriate services, financial burden and emotional strain due to prolonged care-taking, to mention a few (Hubert, 1985; Kosciulek, 1997; Tyerman, 1996).

Changes that are commonly observed in brain injured individuals and the reactions of their care givers are presented next. Although these changes are discussed separately, it should be remembered that they overlap a great deal.

6.1.1. Cognitive changes

Like in most studies, the types of cognitive problems often reported were impairment in learning and memory, both visual and verbal, and planning ability (Brooks, 1984b; Lezak, 1995; Kinsella, 1998). Because of this cognitive deterioration, some care givers spent long hours taking care of the patients with very little appreciation by some family and community members. Deficits involving cognitive and emotional components of behaviour reduced the capacity for spontaneous recall and fore thought and thus restricted mental existence to the immediate here-and-now. Others retained relatively intact time perspective but had difficulty organizing, ordering and integrating their thoughts and experiences. Still others had a diminished capacity to spontaneously generate ideas or initiate activities. A considerable number had difficulty planning and have therefore been unable to take adequate charge of their lives.

Some patients failed to learn from their past experiences, mainly because they did not have insight, yet they were treated with the dignity and respect they deserved, that is, ubuntu still dominated in how they were treated. This is contrary to what Miller (1991a, p.16) says, "One common error made by families ... is treating the patient like a willful or neglectful teenager who should be allowed to make his own mistakes and thereby 'learn what real life is like'".

Though some care givers were at first impatient, they understood their charges' behaviours to be beyond their control either due to thwasa, God's wish, witchcraft, or an accident which, Delehanty and Kieren (1998) associate with sin.

6.1.2. Emotional changes

As indicated earlier, a variety of emotional changes occurred after brain injury that families found difficult to comprehend. These include apathy, silliness, irritability, anger and depression (Lezak, 1988; Miller, 1991a). Most caregivers complained about these changes and wanted some advice on how to handle them. However, others assumed that these emotional displays were deliberate and spiteful. According to Miller (1991a) there may actually be a willful motivation behind the obnoxious emotionality, the patient taking advantage of the symptom to express anger/resentment. But in the other instances, they could not help it because they are disinhibited.

Of all the emotional changes, depression is the most devastating both to the patients and their families. Whether organic (due to damage to different parts of the brain involved in the experience and expression of mood states and emotional behaviour) or reactive depression (an emotional reaction to the changes produced by the injury), it presents the family with emotional behaviour that is unsettling and difficult to deal with. It tends to feed on and exacerbate the patients' emotional and social maladjustment, setting up one of many vicious cycles which the patients and family must address. The patients' depression eroded some family members' self-esteem and increased their feelings of guilt and inadequacy, since the depressed mood and behaviour were so refractory to their best effort to relieve it (Miller, 1991b).

6.1.3. Personality changes

Coupled with emotional changes, families noted changes in personality. As alluded to earlier, personality changes among others, constitute more of a burden on the family than physical disability and are relatively long standing (Brooks, 1984a). Some of the patients were rendered

quieter and more tractable. Some care givers perceived post injury personality changes as distinctly negative, particularly problems with irritability, temper, asponaneity, restlessness and childishness (Miller, 1991b).

Aggressive behaviour syndromes occurred after brain injury which could be related to one or all of the following, paroxysmal episodic dyscontrol, frontal lobe disinhibition or exacerbation of premorbid personality traits. Lezak (1978) is of the opinion that many patients are frustrated and frightened by their conditions, feel an unworthy and unwanted burden on their families, are demeaned and humiliated by the care they need and yet are fearful of losing it. As the ever-present reminders of their dependency and incompetency, some care givers became the focus of the patients' bitterness. Family members, particularly spouses and dependent children were verbally abused. This finding is in line with Miller's (1991a).

6.1.4. Psychiatric changes

Brain injury usually changes the social functioning of both patients and families (family system). When the mental functioning of a previously introspective and self-aware person is impaired by brain injury his/her experience of him/herself and the world changes. This internal disorientation often produces anxiety. According to Lezak (cited in Miller, 1991a, p.16) "...anxiety arising from awareness of one's altered mental status tends to erode the patients self-confidence, to make him or her overly cautious and vigilant and to foster feelings of inadequacy, confusion and even fears of 'going crazy'". Anxiety also may arise out of fears of losing control, especially in patients who retain enough insight into their deficits to be aware of how their behaviour has deteriorated. On the other hand brain injury was noted to impose a state of dependency on once- assertive, self assured independent individuals.

Some patients and their caregivers showed signs of paranoia, suspecting that they were bewitched by their neighbours who were jealous of their achievements (finishing at the university or having a well cared family).

6.1.5. Social changes

Most moderately to severely impaired patients are dependent on their families for some important aspects of their physical care and financial support. Although Miller (1991b, p.18) is of the opinion that "...when the patients needs finally exceed the family's capacity to provide and the patient's care must be obtained from agencies outside the family, many caretakers feel guilty and ashamed for what they regard as their failure to 'do right by their loved one'". This was not the case in this study. According to the African philosophy of Ubuntu (motho ke motho ka batho ba bang-One's humanity is dependent on other people) , it is acceptable to accept help from others, as they will accept it from you one day.

In other families, parents reinforced the patient's dependency. In some cases, child-like dependency that was intolerable to the spouse was perfectly acceptable to parents and was actually encouraged. For many parents of adolescent or/and young adult patients, caring for the now-dependent offspring was their only way to get back their son/daughter whose behaviour had previously been seen as out of control. Caregivers also felt socially isolated because they did not have time to attend community/social gatherings (Miller, 1991b).

6.2. Reactions Of Family Members To Caring For And Living With A TBI Patient

While the individual reactions of families to the brain injured loved ones are in some respects unique to each family situation, a number of typical clusters of family reactions patterns are presented next.

6.2.1. Denial

Families wanted to believe that their loved one would get better, would "return" to them in some reasonable semblance of his/her former self. According to Rosenthal and Young (1988),

denial is adaptive when it preserves family stability, keeps the family members from being overwhelmed and maintains appropriate role functioning of all family members. Denial is maladaptive when it impedes progress towards functional independence or when it prevents realistic planning for the future.

The results of this study suggest that denial was partly a result of lack of information about TBI. Family denial was prolonged by fantasies that patients would return to their former selves if given enough time or if the “right” traditional treatment was given and appropriate traditional rites performed. These denials have a strong cultural base and therefore sustain the hope of both patients and families that someday things would be normal again.

Perceptions like TBI is God’s wish, witchcraft, ancestral anger, thwasa and Satanism to mention a few, are functional denial, because they help African families to cope with TBI. According to Miller (1991a; 1991b) denial leads to interminable “shopping around” for treatment facilities and medicines to mention a few, as a way of avoiding the setting of less-than-perfect goals, something never found in this study.

6.2.2. Feeling trapped

According to Lezak (1978), feeling trapped is an almost universal reaction of family members to living and caring for a brain injured person. Though this was true for some in the present study it was not for the majority. Some families believed that God and ancestors wanted them to look after the patients and that God’s or ancestors’ instructions should not be equated and identified with traps. They felt lucky to be looking after the patients and doing what God and ancestors expected of them. This perception too has a cultural base (*Ha ho motse osenang sehole* – There is no family without a physically challenged person). If, before the injury no one was physically challenged in the family, the injury normalises the situation. Hence it is easier for some families to accept. Some did feel trapped and this led to divorcing the patients as a way of

getting free from the trap. This is a phenomenon common with spouses of TBI patients, due to loss of empathic sensitivity and continual blaming. Blaming renders the whole family dysfunctional (Naugle, 1990).

6.2.3. Isolation

Congruent with Lezak's (1978) findings, some family members felt socially isolated as a result of caring for the patients. Some house-bound patients required full-time attention and care. Other patients embarrassed the family in public and became belligerent with strangers (visitors). It is in such cases where families decided it was easier and more comfortable to stay home.

The families of patients got further isolated when extended family members (uncles, aunts, cousins and in-laws) stopped visiting. Matters are made worse when outside relatives take a hands-off attitude with respect to day-to-day care giving responsibilities and may be quick to offer sharp critiques of how the immediate family is doing their job. This is most likely to produce secondary conflict in terms of family bitterness and resentment.

However, in small rural communities, a sense of cohesion is still strong. Long after the injury, extended family members and neighbours still showed their support and ubuntu.

6.2.4. Depression

Just as brain injury may cause depression in a patient, the family may also be affected. According to Lezak (1978), most family members who live with brain injured patients suffer some degree of depression, shown by anxiety and agitation, obsessive rumination, lethargy and fatigue, disturbed sleep and appetite. In this study when patients were depressed their caregivers were also depressed, which suggests that depression affects the whole family system.

6.2.5. *Family role change*

Brain injury may involve a loss of important qualities that were part of the patients' premorbid cognitive and personality pattern and this may force other family members into unaccustomed and unwanted roles. For example, a previously dependent and submissive family member may have to assume responsibility and make decisions (McKinlay & Hickox, 1988). It is during this time that some felt unable to take decisions for the whole family. In these instances, they escaped through divorce or staying with other relatives in far away places. The new roles family members were expected to play were stressful (Fujii et al., 1996). Tyerman (1996, p. 105) found that in families "...with very severe injuries, primary carers rated families as less cohesive, to have more conflicts, to be less active socially, to have more external locus of control, to be less like the ideal family and to have increased enmeshment and decreased disengagement...". Most of his findings are confirmed in the present study, for example, the level of social activity and enmeshment were consistent with Tyerman's (1996) findings. However, there are some contradictions that emerged, for example, this study found that some families with severely injured patients became more of ideal families with fewer conflicts and more cohesion. This was due to cultural factors and practices like ubuntu.

6.3 Implications For Rehabilitation

It should be noted with interest that the same problems discussed in the literature are experienced by the respondents (co-researchers) in the present study. The implication thereof is that the consequences of TBI are universal. What differs are peoples' interpretations and experiences of the phenomenon, due to cultural factors.

As alluded to earlier, brain injury is a family matter. Therefore rehabilitation is by implication a family matter. It should be remembered that families in this study come from previously disadvantaged communities. The contention here is that something befitting these communities should be suggested with the hope of making health services effective for them, taking cultural

factors into account.

It is imperative to note that patients have rights enshrined in the constitution of this country (Constitution of RSA, 1996). Despite the statutes of the constitution, in the eastern Free State, as is the case in almost all provinces, there are very few rehabilitation and retraining centres to assist patients and their families to return to an independent and productive role in society.

Rehabilitation should be understood as an intervention, the purpose of which is to ease the transition of the patient into his/her new role within the family and community and facilitate adjustment to changed roles on the part of other family members (Miller, 1991a). As indicated above, the consequences of TBI are devastating to both patients, especially those who have insight into their impairment, as well as their families, particularly primary caregivers. However, the important question that arises at this stage is: If most families interviewed are coping because of cultural beliefs, why should I propose a rehabilitation program that may question those beliefs? The simple answer is that what is suggested here is not cast in stone. It could be useful for families that are not coping, those that are coping but would want to enhance their coping mechanisms and at the same time contribute valuable information/knowledge to the field of neuropsychological rehabilitation, particularly for Africans.

In addressing the rehabilitative needs of both patients and their families, the following interventions, among others, could be resorted to, namely, education, support groups, networking, advocacy and family therapy (Delehanty & Kieren, 1998; Fujii et al., 1996; Iverson & Osman, 1998; O'Hara & Harrell, 1991; Miller, 1991b).

Fujii et al. (1996) cited education as one of the most needed and valuable forms of intervention. In this study it was found that almost all participants regardless of their level of education did not have much knowledge of TBI. Some caregivers and patients with well above grade twelve education hoped that one day patients would have fully recovered and would be able to resume their pre-injury responsibilities. It is therefore important that caregivers should be

educated, that is, be given information about the nature and prognoses of TBI and intervention strategies. This kind of education can reassure overwhelmed family members and help them to develop realistic expectations and improve their caregiving skills. Expert educators to be used here are rehabilitated patients and their caregivers, working closely with neuropsychological rehabilitation experts. One of the most important experts in African communities is the indigenous healer. The indigenous healer is perceived as a psychologist, physician, priest, prophet, carrier of ancestral voices and a tribal historian. He has established credibility and a pervasive influence in the community (Hickson & Kriegler, 1991; Holdstock, 1979; Kriegler, 1993; Stones, 1996).

As found in the present study, most Africans in townships, rural and semi-rural areas believe that their ailments, whether physical and/or psychological including TBI are due to sorcerers/witches or to spells cast at the instigation of those who do not like them. The issues of witchcraft, thwasa and ancestral anger are matters the indigenous healer is qualified to deal with. Therefore, people should be aware that indigenous healers are in many instances more effective than often believed. They have been looking after the mental well-being of Africans throughout the course of African civilisation. They have played a significant role in addressing the problem of geographical inaccessibility of psychological services to most Africans, although some health professionals still perceive them as obstacles to good health care in general. This is the failure on the part of such professionals to acknowledge the role played by these healers in for example, the treatment of tuberculosis (by helping nurses to encourage patients to adhere to their treatment) and Aids (by helping with the distribution of condoms). The mis-conception about indigenous healers needs to be corrected (Berger & Lazarus, 1987; Freeman, 1991; Holdstock, 1979; Kriegler, 1993). It is imperative that such healers be taught about TBI and be used to teach some families and patients who regularly come to see them for treatment. Education by indigenous healers is likely to be more acceptable to more traditional African families rather than westernised professionals.

It may be that once care givers are educated about TBI they might be devastated, bearing in

mind that lack of information keeps them hopeful. Nevertheless, they have the right to information, and professional ethics dictates so. The best ways of dealing with this devastation are, among others, the formation of support groups, social networking, advocacy and family therapy which are presented below.

Support groups that can provide a forum for sharing feelings and exploring alternative ways of dealing with difficult situations should be formed. Support groups could be useful in that they could provide opportunities for emotional support, education and networking (Baron & Byrne, 1997; Fujii et al., 1996; O'Hara & Harrell, 1991). Headway (internationally based) and BrainStomers (based in America), which are support groups for traumatically brain injured individuals and their families, could be used as a models of organising these support groups (Brown et al., 1997; Headway, personal communication, July 23, 2000).

Social networking entails extending family and social systems to identify and solicit resources that can strengthen family functioning and/or assist in the care of the brain injured members. An extension of this intervention could be to establish community centers manned by volunteers, rehabilitated patients and their families. If parents want to go out for a weekend, they should be able to leave their loved ones at such a center at a reasonable cost. These centers should also cater for parents/spouses who want to leave their loved ones for few hours. The donations for this service could be used to sustain the center. Programs running at such centers should include among others, behavioural contingency management, academic and social skills training, counselling and family education. Vocational rehabilitation programs should also be put in place at this centers. A program suggested by Tyerman (1996) comprising three phases, namely, remedial intervention, guided occupational trials and vocational placements could be considered. The first phase comprises intensive individual and group intervention focusing on cognitive remediation, self-awareness and social skills. The second phase is voluntary occupational trials prior to progressing to the third phase which is a suitable work placement.

Advocacy is another rehabilitation strategy that can be implemented. This strategy involves

helping families take full advantage of existing community resources, modifying existing resources so that they provide better services for the patients, and developing new services that are currently unavailable. Traditional healers and Christian groups can play a major role here. According to Fujii et al. (1996) networking and advocacy are especially important for community reintegration of the patients through the attainment of services and increasing involvement in the community. The two strategies, namely, networking and advocacy are an integral part of ubuntu, so they will be easily accepted by the community members.

Family therapy is strongly indicated. According to Rosenthal and Young (1988) the appropriate family therapy is one that assists the family in realistically appraising the impact of the injury on the family functioning and their loved one. Additionally, the therapy should maximise the family's capability in managing the multiple disabilities that have emerged out of the brain injury.

6.4. Reactions Of Families To The Recommended Rehabilitation Strategies.

In line with the spirit of recursivity, the suggested recommendations were taken back to all participants to get their views(member validation/checks). Their responses are discussed next.

6.4.1. Education.

A majority of the families who perceived TBI as either thwasa, witchcraft and ancestral anger indicated that they would not attend information sessions because people who would facilitate them would be operating from western perspective. They would not feel comfortable working with such facilitators because they are aggressive. A small number of those who perceived TBI as either thwasa, witchcraft or ancestral anger indicated their willingness to attend. Their motivation is well captured by the one who said they would "... attend such educational sessions in order to get other people's views and see if we can not benefit". These are the people who desperately look for advice on how to deal with their changed relatives. They are prepared to

attend any gathering so long as they would benefit and feel in control of the situation.

On the involvement of traditional healers in this information sessions(educating families about TBI) the majority indicated that it would be a good idea since they believed that traditional healers are regarded as people who are qualified to deal with traditional perceptions. However, others were of the opinion that such traditional healers are bogus healers and traitors since by their participation in such a project they would not be serving ancestral interests. According to them “... traditional healers should stay away from controversies and carry out what they have been called to do, that is, divining and dispensing muti).

6.4.2. Advocacy, support groups and networking.

A majority of those who perceived TBI as a consequence of an accident, God’s will and Satanism strongly supported advocacy, formation of support groups and networking. Most of these families also indicated that they would attend information sessions which they thought would give them a sense of direction and a solid grounding on matters relating to TBI. In support of advocacy, they indicated that they would be instrumental in converting some existing building into rehabilitation centers and pressurising the provincial government to fund their efforts as “...there are no appropriate services for brain injured individuals”. A few families raised their concern about joining advocacy and support groups. One care giver said “ Though we would join such groups, it would be difficult to disclose confidential family information to support and advocacy group members. I think most of us would be a bit passive for the first two or so meetings... trying to test the waters”.

Still a few families felt that they get support from their fellow congregants as a result they would not join such groups. Their fear was that if they join such groups, they would be easily derailed by evil spirits, as a result it would be in their interest to “...stick to Godly things”. The other thing they would not do is to attend any activity steered by a traditional healer because they regarded their activities as evil and ungodly. This confirms the necessity of taking individual

needs into account when planning rehabilitation. In this particular instance, the involvement of the church (Christian) community would be important.

6.4.3. Vocational rehabilitation.

All participants regarded vocational rehabilitation as a good way to keep patients occupied within a safe environment. If well structured, it would also give caregivers a break when patients are away. The other positive point was that once patients are placed at a work station, they would be able to contribute towards their accommodation, food and medical expenses. It is also at these placements where brain injured individuals would be afforded the opportunity to interact socially and befriend others. While away on placements, caregivers would be able to attend to other family chores and errands.

6.4.4. Family therapy

As alluded to earlier, the participants came from a disadvantaged community and as a result almost all of them have not had contact and/or knowledge of western-trained psychotherapists. However, after explaining how psychotherapists work, a few families felt comfortable with the idea of attending family therapy sessions. Still a few expressed their doubts saying "... it is too early to say whether we would participate or not ...". However, with appropriate persuasion including giving the relevant information and explaining the merits of participating, these people are likely to participate.

6.5. Upsetting The Equilibrium By Introducing The Recommended Rehabilitation Strategies.

As mentioned earlier, rehabilitation is virtually non-existent in rural areas. Introducing rehabilitation services may amount to questioning the belief system of the African families, who are coping with TBI through their cultural beliefs. Nevertheless, if some are able to benefit from

rehabilitation, the proposed intervention could contribute to social change. What is important to remember though is that not all individuals will be receptive to the information and the ideas. Because of the enthusiasm of some and the reluctance of others, some will be slow but will eventually adopt the innovative ideas, while others will never adopt them. There could be two reasons for this, the firstly being personal characteristics (which includes cultural beliefs). For example, some individuals are closed minded or dogmatic. This implies that they will not accept new ideas readily, in fact they might not accept the ideas at all. Other individuals may find themselves in a social context where the suggested strategies are unacceptable and as a result conform with the community 's wishes and cultural norms by not adopting them, no matter how good they might be.

On the other hand, there are flexible individuals who are able to adapt to new ideas and may adopt them after scrutinising them thoroughly and appreciating their merits. Normally, these are the people whose influence is pervasive in their communities. As alluded to earlier, one such person is a traditional healer. Therefore, traditional healers will play a crucial role in the implementation of the proposed strategies. The anxiety which may be provoked by these rehabilitation strategies can be addressed by the *culturally sensitive nature* of the implementation strategy. This refers to the fact that use will be made of known and respected community members. External experts will only be included after obtaining entry into the communities. External experts who should coordinate the process should also be patient and wait for the entire process to unfold, that is, give families enough time to make up their minds about participating and facilitate their involvement slowly.

As observed earlier, the implementation of these strategies might upset participants' traditional beliefs that have been helping them to cope. Change, in whatever form is stressful. Nevertheless, unplanned change is more stressful than the planned change. Patients can be given the opportunity of changing their situation through information about rehabilitation. Their right not to participate should be respected. However, adhering to the status quo in the name of being culturally sensitive may violate human rights and professional ethics.

As much as the implementation of affirmative action and gender equality challenged the traditional beliefs of both whites and men (both black and white) many have adapted to the changed situation. Even though most people got upset in the beginning, things have changed for the better. In the case of these rehabilitation strategies, rural people may feel challenged but may accept them with time and if the matter is dealt with sensitively. The education (information dissemination) and therapy in its many forms, among other interventions can help them cope with the loss of what was up to this stage closer to their hearts, namely cultural beliefs. In the long run, they are likely to realise the benefits of these strategies if their lives change for the better.

6. 6. The Researcher's Role In The Study

At this point, the researcher would like to take a meta-position and comment on his role in this study. On the basis of this, he would like to shed the academic mask and use the pronoun "I".

In this study, I have been the primary data collection instrument. This implies that I brought biases and idiosyncratic ideas with me to the study. Such biases and idiosyncratic ideas are consonant with an ecosystemic epistemology, which emphasises that reality is observer-dependent, that is, reality is subjective. Second order cybernetics maintains that the observer forms part of the observed. The implication thereof is that this research was not done on the co-researchers, but with them. Hence they are not referred to as subjects but as co-researchers (Atkinson & Heath, 1987; Maturana & Varela, 1992; Moon et al., 1990).

Fourie (1996), Hoffman (1990) and Keeney and Morris (1985) maintain that any statement about a system or an observation is a statement about the observer's opinion, ideas and ways of thinking rather than about that particular system or observation. This study therefore reveals my own interpretation and conclusion about African families' perceptions of TBI and its consequences. Therefore, the findings and the recommendations are not cast in stone. They only reflect the "reality" of a particular group of co-researchers that was elicited by a particular

researcher at a certain time. Therefore the findings and the recommendations suggested here can not be generalised but adapted after thorough investigations (Colapinto, 1979; Lincoln & Guba, 1985; Maturana & Varela, 1992).

6.7. Limitations And Suggested Follow Up Studies

The first limitation of the present study is about the selection of participants. Anybody who had TBI, regardless of its severity was selected to participate, in other words, the selection process neglected the fact that TBI can be of varying severity ranging from mild, moderate to severe. As noted in chapter 2, the severity of TBI depends on numerous factors, for example, alteration in the level of consciousness, post traumatic amnesia, physiological and radiologic evidence. In other words, varying severity of TBI which is determined by the above indicated factors results in different sequelae. Taking all these factors into consideration, the findings of the present study are not equally applicable to all participants.

Linked with the above, is the study's proclivity to work from the general approach than from an individualised approach thereby lumping all participants into one basket. This is not fair , bearing in mind that each family has its unique experiences and views which do not necessarily fit well into the presented themes. It may appear that the generalised approach does not enrich rehabilitation to the extent the individualised approach does. However, it gives another perspective.

As has been alluded to earlier, my personal values and experiences may have influenced the study. After all, Creswell (1998, p. 55) says the following about the phenomenological approach "Bracketing personal experiences by the researcher may be difficult", however, " The researcher needs to decide how and in what way his or her personal experiences will be introduced into the study". So, awareness of the influence of personal biases and experiences lessens the seriousness of this limitation.

Lastly, it is recommended that a follow-up to this study be conducted so as to assess kinds of rehabilitation approaches that are effective in the African community.

Conclusion

In conclusion, this study confirms the findings of previous studies, that traumatically brain injured people and their families experience a range of personal and social problems. In the geographical areas where the current study was conducted, this should be seen in the context of virtually no rehabilitation services. As the study indicates, there is a significant number of brain injured people who are struggling together with their families without the benefit of appropriate assessment and/or rehabilitation. There is evidence from rehabilitation studies suggesting that social outcome can be improved for some traumatically brain injured individuals, thereby reducing the stress on the family system (Miller, 1991b; Tyerman, 1996). However, many participants in the present study indicated their uncertainty about rehabilitation and therapeutic intervention. These uncertainties can be addressed by disseminating information (education).

Families should be given information about TBI and natural reactions to head injury. It is natural to be angry, feel guilty and use denial as well as other coping mechanisms in some situations after a head injury or when any other traumatic event happens to a family. Families often experience years of difficulties that bring on emotional reaction before they realise the reaction is part of the coping process. If families are supported to express these emotions and use the coping mechanisms available to them, they may deal with the daily reality of brain injury effectively.

Although it has been recommended that rehabilitation strategies like education, support groups, networks and advocacy should be used in the rehabilitation process, it is important to note that the complex needs arising from brain injury are such that no one agency can hope to develop an all-inclusive service. Implementation of the required components of rehabilitation

will depend on the pattern of the established and/or existing local and regional services. In order to render the best service, representatives of social, employment, education and voluntary services and the affected families need to be involved in joint planning and monitoring. This would embrace culturally relevant beliefs and practices which would make the interventions more acceptable and effective.

Services should support, not supplant the families' coping resources. Families should be given enough information early so as to assist them understand options and choices. The many trappings of medical jargon and expert advice should be replaced with clear, concise information and support as a basis for making sensible decisions.

Though the intention of this study was to give a thick description of African families experiences, views, cultural beliefs and interpretation of traumatic brain injury, it co-incidentally implemented some of the proposed rehabilitation strategies, namely education/information dissemination (where participants asked questions for clarification) and therapy. So, the study has laid a foundation for the possible implementation of its recommendations. Lastly, it is the contention of this study that African cultural beliefs should not be undermined, rather, they should be incorporated into the rehabilitation process.

LIST OF REFERENCES

- Atkinson, B. J. & Heath, A. W. (1987). Beyond objectivism and relativism: implications for family therapy research. *Journal of Strategic and Systemic Therapies*, 6(1), 8-17.
- Baron, R. A. & Byrne, D. (1997). *Social psychology* (9th. Ed.). Boston: Allyn & Bacon.
- Beaver, M. (1991). Special issues for a spouse. In J.M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 19-23). London: Paul H Brooks.
- Becvar, D. S. & Becvar, R. J. (1996). *Family therapy: a systemic integration*. 3rd. Ed. Boston: Allyn & Bacon.
- Bennum, I. (1994). Marital conflict: Treatment. In S. J. E. Lindsay & G. E. Powell (Eds.), *The handbook of clinical adult psychology* (2nd. Ed., pp.283-294). London : Routledge.
- Berger, S. & Lazarus, S. (1987). The views of community organizers on the relevance of psychological practice in South Africa. *Psychology in Society*, 7, 24-35.
- Beuster, J. (1997). Psychopathology from a traditional South African perspective. *Unisa Psychologia*, 24(2), 4-16.
- Bless, C. & Higson-Smith, C. (1995). *Fundamentals of social research methods: an African perspective* (2nd. Ed.). Cape Town: Juta.
- Bond, M. R. (1983). Effects on the family system. In M. Rosenthal, E. Griffith, M. Bond & J. D. Miller (Eds.), *Rehabilitation of the head injured adults* (pp. 209-217). Philadelphia : F. A. Davis.
- Bond, M. (1984). The psychiatry of closed head injury. In N. Brooks (Ed.), *Closed head injury: psychological, social and family consequences* (pp. 148-178). Oxford: Oxford.
- Brooks, N. (1984a). Head injury and the family. In N. Brooks (Ed.), *Closed head injury: psychological, social and family consequences* (pp. 123-146). Oxford: Oxford.
- Brooks, N. (1984b). Cognitive deficits after head injury. In N. Brooks (Ed.), *Closed head injury: psychological, social and family consequences* (pp. 44-73). Oxford :Oxford
- Brown, N., Darling, P., Hardman, J., Lonseth, A., Rieger, D., Rousseau, G., Seiler, T., Ward, E., Weber, R. & Wright, S. (1997, July/August). Negotiating the possible: Issues and strategies for survivors with newly acquired brain injury. *The Journal of Cognitive Rehabilitation*, 20- 23.
- Buhrman, M. V. (1986). *Living in two souls*. Illinois: Chiron.

- Campbell-Korves, M. (1991). Special issues for a person with a head injury. In J. M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 3-8). London: Paul H Brooks.
- Capra, F. (1983). *The turning point: science, society and the rising culture*. London: Flamingo.
- Colapinto, J. (1979). The relative value of empirical evidence. *Family Process*, **18**, 427-445.
- Cresswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage.
- Dell, P. F. (1985). Understanding Bateson and Maturana: Towards a biological foundation for the social sciences. *Journal of Marital and Family Therapy*, **11**(1), 1-20.
- De Velliers, S. (1985). Illness causation among some Xhosa-speaking people. *South African Journal of Psychology*, **8**, 48-52.
- Delehanty, R. & Kieren, D. (1998). Family perceptions of health professionals in family problem solving after brain injury. *Journal of Cognitive Rehabilitation*, 14-23.
- Della Sala, S. & Logie, R. H. (1997). Impairments of methodology and theory in cognitive neuropsychology: a case for rehabilitation. *Neuropsychological Rehabilitation*, **7**(4), 367-385.
- Dr. Watts. (2000, July 23). *Personal communication*
- Fernando, S. (1991). *Mental health, race and culture*. London: MacMillan.
- Fife, D., Faich, G., Hollinshead, W. & Boynton, W. (1986). Incidence and outcome of hospital-treated head injury in Rhode Island. *American Journal of Public Health*, **76**, 773-778.
- Fourie, D. P. (1996). Capitalising on concepts in hypnotherapy: the theory of ecosystemic practice. *Hypnosis International Monographs*, **2**, 119-130.
- Freeman, M. (1991). Mental health for all- moving beyond rhetoric. *South African Journal of Psychology*, **21**, 141-147.
- Fujii, D., Hanes, S. S. & Kokuni, Y. (1996). Family intervention in the rehabilitation and community reintegration of individuals with brain injury. *Journal of Cognitive Rehabilitation*, 6-9.
- Gergen, K. J. (1991). The post-modern family: the saturated family. *Networker*, 27-35.
- Gordon, J. R. (1993). *A diagnostic approach to organizational behaviour* (4th Ed.). Allyn & Bacon.

- Guba, E. G. & Lincoln, Y. S. (1988). Do inquiry paradigms imply inquiry methodologies. In D. M. Fetterman (Ed.), *Qualitative approaches to evaluation in education: the silent revolution* (pp. 76-105). New York: Praeger.
- Hammersley, M. (1996). The relationship between qualitative and quantitative research: paradigm loyalty versus methodological eclecticism. In J. T. E. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social science* (pp. 159-174). Leicester: BPS.
- Hammond-Tooke, W. D. (1989). *Rituals and medicines*. Johannesburg: A. D. Donker.
- Hammond-Tooke, W. D. (1975). African world-view and its relevance for psychiatry. *Psychologic Africana*, **16**, 25-32.
- Hardgrove, H. (1991). Special issues for a child. In J.M. Williams & T. Kay (Eds.), *Head injury: a family matter*. (pp. 25-270). London: Paul H Brooks.
- Headway (2000, July 23). *Personal communication*
- Henwood, K. L. (1996). Qualitative inquiry: perspectives, methods and psychology. In J. T. E. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences* (pp. 86-101). Leicester: BPS.
- Hickson, J. & Kriegler, S. (1991). The mission and role of psychology in a traumatised and changing society. *International Journal of Psychology*, **26**, 783-793.
- Hitchcock, G. & Hughes, D. (1989). *Research and the teacher: a qualitative introduction to school based research*. London: Routledge.
- Hoffman, L. (1990). Constructing realities: an art of lenses. *Family Process*, **29**, 1-12.
- Holdstock, T. L. (1979). Indigenous healing in South Africa: a neglected potential. *South African Journal of Psychology*, **9**, 118-124.
- Hubert, J. (1995). *Life after head injury*. Aldershot: Avebury.
- Iverson, G. & Osman, A. (1998). Behavioral interventions for children and adults with brain injuries: a guide for families. *Journal of Cognitive Rehabilitation*, 14-15.
- Jansen, P. (1989). *Mild and moderate head injury: a follow up study*. Unisa, Institute of Behavioural Sciences.

- Jansen, P., Richter, L. M., Griesel, R. D. & Joubert, J. (1990). Glue sniffing: A description of social, psychological and neuropsychological factors in a group of South African "street children". *South African Journal of Psychology*, **20**(3), 150-158.
- Jennett, B. (1984). The measurement of outcome. In N. Brooks (Ed.), *Closed head injury: psychological, social and family consequences* (pp. 37-43). Oxford: Oxford.
- Johnson, A. R. (1993). *Epistemology and psychotherapy: A dialogue between phenomenology and cybernetics*. Unpublished doctoral thesis, University of South Africa, Pretoria
- Johnson, R. (1998). How do people get back to work after severe head injury ? A 10 year follow up study. *Neuropsychological Rehabilitation*, **8**(1), 61-79.
- Kaplan, P. S. (1990). Social support, emotional distress and vocational outcomes among persons with brain injuries. *Rehabilitation Counselling Bulletin*, **34**, 16-23.
- Keeney, B. P. & Morris, J. (1985). Implications of cybernetic epistemology for clinical research: a reply to Howard. *Journal of Counselling and Development*, **63**, 548-550.
- Keeney, B. P. & Ross, J. M. (1992). *Mind in therapy: constructing systemic family therapy*. Pretoria: Unisa.
- Kinsella, G. J. (1998). Assessment of attention following traumatic brain injury: a review. *Neuropsychological Rehabilitation*, **8**(3), 351-375.
- Kosciulek, J. F. (1997). Dimensions of family coping with head injury: a replication and extension. *Rehabilitation Counselling Bulletin*, **41**(1), 43-52.
- Kramer, J. (1991). Special issues for a parent. In J.M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 9-17). London: Paul H Brooks.
- Kreutzer, J. S., Zasler, N. D., Camplair, P. S. & Leininger, B. E. (1990). A practical guide to family intervention following adult traumatic brain injury. In J. S. Kreutzer & P. Wehman (Eds.), *Community integration following traumatic brain injury* (pp. 249-273). London : Wiley.
- Kriegler, S. (1993). Options and directions for psychology within a framework for mental health services in South Africa. *South African Journal of Psychology*, **23**, 64-70.
- Kvale, S. (1994). Ten standard objections to qualitative research interviews. *Journal of Phenomenological Psychology*, **25**(2), 147-173.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. London: Sage

- Levin, H. S., Benton, A. L. & Grossman, R. G. (1982). *Neurobehavioural consequences of closed head injury*. New York: Oxford.
- Leyland, M. L. (1988). An introduction to some of the ideas of Humberto Maturana. *Journal of Family Therapy*, **10**, 357-374.
- Lezak, M. D. (1978). Living with the characterologically altered brain injured patients. *Journal of Clinical Psychiatry*, **39**, 592-598.
- Lezak, M. D. (1986). Psychological implications of traumatic brain damage for the patients' families. *Rehabilitation Psychology*, **31**(4), 241-250.
- Lezak, M. D. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology*, **10**, 111-123.
- Lezak, M. D. (1995). *Neuropsychological assessment*. 3rd Ed. New York: Oxford.
- Lezak, M. D. & O'Brien, K. P. (1990). Chronic emotional, social and physical changes after traumatic brain injury. In E. D. Bigler (Ed.), *Traumatic brain injury: mechanisms of damage, assessment, intervention and outcome* (pp.365-378). Austin: Pro-ed.
- Lincoln, Y. S. & Guba, E.G. (1985). *Naturalistic inquiry*. London: Sage.
- Louw, D. A., Van Ede, D. M. & Louw, A. E. (1997). *Human development*. 2nd Ed. Pretoria: Kagiso.
- Lynch, W. (1984). A rehabilitation program for brain-injured adults. In B. A. Edelstein & E. T. Couture (Eds.), *Behavioural assessment and rehabilitation of the traumatically brain-damaged* (pp. 273- 312). New York : Plenum.
- Maitz, E. A. (1991). Family systems theory applied to head injury. In J.M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 65-79). London : Paul H Brooks.
- Marquardt, T. P., Stoll, J. & Sussman, H. (1990). Disorders of communication in traumatic brain injury. In E. D. Bigler (Ed.), *Traumatic brain injury: mechanisms of damage, assessment, intervention and outcome* (pp. 181-205). Austin: Pro-ed.
- Marshall, C. & Rossman, G. (1995). *Designing qualitative research*(2nd Ed.). Thousand Oaks: Sage.
- Martin, D. A. (1990). Family issues in traumatic brain injury. In E. D. Bigler (Ed.), *Traumatic brain injury: mechanisms of damage, assessment, intervention and outcome* (pp. 381-394). Austin: Pro-ed.

- Massarik, F. (1981). The interviewing process re-examined. In P. Reason & J. Rowan (Eds.), *Human inquiry : a sourcebook of new paradigm research* (pp. 201-206). Chichester: Wiley.
- Maturana, H. (1975). The organization of the living : A theory of the living organization. *International Journal of Man-Machine Studies*, 7, 313-332.
- Maturana, H. R. & Varela, F. J. (1992). *The tree of knowledge: the biological roots of human understanding* (Rev. Ed.). Boston : Shambhala.
- Maurer, J. (1991). Specific issues for a sibling. In Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 29-33). London: Paul H Brooks.
- Mbiti, J. S. (1969). *African religion and philosophy*. London: Heinemann.
- McKinlay, W. W. & Hickox, A. (1988). How can families help in the rehabilitation of the head injured ? *Journal of Head Trauma Rehabilitation*, 3(4), 64-72.
- Miller, L. (1991a). Psychotherapy of the brain-injured patient: principles and practice. *Cognitive Rehabilitation*, 24-30
- Miller, L. (1991b). Significant others: treating brain injury in the family context. *Cognitive Rehabilitation*, 16-25.
- Moon, S. D., Dillon, D. R. & Sprenkle, D. H. (1990). Family therapy and qualitative research. *Family Process*, 16(4), 357-373.
- Moustakas, C. (1994). *Phenomenological research methods*. London: Sage.
- Naugle, R. (1990). Epidemiology of traumatic brain injury in adults. In E. D. Bigler (Ed.), *Traumatic brain injury: mechanisms of damage, assessment, intervention and outcome* (pp. 69-103). Austin: Pro-ed.
- Nell, V. & Brown, D. S. O. (1990). *The epidemiology of traumatic brain injury in Johannesburg: mobility, mortality and etiology*. Unisa Health Psychology Unit, Technical Report 90/1.
- Oddy, M. (1984). Head injury and social adjustment. In N. Brooks (Ed.), *Closed head injury: psychological, social and family consequences* (pp. 108-122). Oxford: Oxford.
- O'Hara, C. C. & Harrell, M. (1991). The empowerment rehabilitation model: Meeting the unmet needs of survivors, families, and treatment providers. *Cognitive Rehabilitation*, 14-21.

- Orto, A. E. D. & Power, P. W. (1994). Head injury and the family: a life and living perspective. In J. S. Kreutzer & P. Wehman (Eds.), *Community integration following traumatic brain injury* (pp. 225-247). Baltimore: Paul H Brooks.
- Owen, I. R. (1992). Theory and practice: applying social constructionism to psychotherapy. *Counselling Psychology Quarterly*, 5, 385-402.
- Penrod, S. (1983). *Social psychology*. New Jersey: Prentice-Hall.
- Pidgeon, N. & Henwood, K. L. (1996). Grounded theory: practical implications. In J. T. E. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences* (pp. 86-101). Leicester: BPS.
- Powell, G. E. & Wilson, B. A. (1994). Introduction to neuropsychology and neuropsychological assessment. In S. J. E. Lindsay & G. E. Powell (Eds.), *The handbook of clinical adult psychology* (2nd Ed., pp. 645-687). London : Routledge.
- Prigatano, G. P. & Parsons, O. A. (1976). Relationship of age and education to Halstead test performance in different patient populations. *Journal of Consulting and Clinical Psychology*, 44, 527-533.
- Reason, P. & Rowan, J. (1981). On making sense. In P. Reason & J. Rowan (Eds.), *Human inquiry: a sourcebook of new paradigm research* (pp. 113-137). Chichester: Wiley.
- Republic of South Africa: Constitution* (1993, Act 200). Pretoria: Government Printers.
- Rosenthal, M. (1984). Strategies for intervention with families of brain injured patients. In B. A. Edelstein & E. T. Couture (Eds.), *Behavioural assessment and rehabilitation of the traumatically brain damaged* (pp. 227-247). New York: Plenum.
- Rosenthal, M. & Young, T. (1988). Effective family intervention after traumatic brain injury: Theory and practice. *Journal of Head Trauma Rehabilitation*, 3(4), 42-50.
- Schreier, R. J. (1985). *Constructing local theologies*. Britain : SCM.
- Simon, R. (1985, May - June). A frog's eye view of the world. *Networker*, 32-43.
- Silver, S. M., Price, P. L. & Barrett, A. (1991). Family and return to work. In J. M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 179-201). London: Paul H Brooks.
- Smith, J. A. (1996). Evolving issues for qualitative psychology. In J. T. E. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences* (pp. 189-201). Leicester: BPS.

- Sohlberg, M. M. & Mateer, C. A. (1990). Evaluation and treatment of communicative skills. In J. S. Kreutzer & P. Wehman (Eds.), *Community integration following traumatic brain injury* (pp. 67-79). London: Paul H Brooks.
- Stones, C. R. (1996). Attitudes towards psychology, psychiatry and mental health in the central eastern Cape of South Africa. *South African Journal of Psychology*, 26, 221-225.
- Swartz, L. (1986). Transcultural psychiatry in South Africa. Part 1. *Transcultural Psychiatric Research Review*, 23, 273-303.
- Tate, R. L. (1998). "It is not only the kind of injury that matters, but the kind of head". The contribution of premorbid psychological factors to rehabilitation. *Neuropsychological Rehabilitation*, 8(3), 351-375.
- Teasdale, G. & Mendelow, D. (1984). Pathophysiology of head injuries. In N. Brooks (Ed.), *Closed head injury: psychology, social and family consequences* (pp.37-43). Oxford: Oxford.
- Turnbull, A. P. & Turnbull, H. R. (1990). *Families, professionals and exceptionality: a special partnership*. Columbus: Charles E Merri.
- Tyerman, A. (1996). The social context. In F. D. Rose & D. A. Johnson (Eds.), *Brain injury and after: towards improved outcome* (pp. 97-116). London: Wiley.
- Vogelman, L. (1987). The development of an appropriate psychology—the work of the organization of appropriate social services in South Africa. *Psychology in Society*, 7, 24-35.
- Von Foerster, H. (1984). An introduction to radical constructivism. In P. Watzlawick (Ed.), *The invented reality* (pp 41-61). New York: Norton.
- Von Glasersfeld, E. (1984). On constructing a reality. In P. Watzlawick (Ed.), *The invented reality* (pp.17-40). New York: Norton.
- Watson, M. J., Horn, S., Wilson, B. A., Shiel, A. & McLellan, L. (1997). The application of a paired comparisons technique to identify sequence of recovery after severe head injury. *Neuropsychological Rehabilitation*, 7 (4), 441-458.
- Williams, J. M. (1991). Family reactions to head injury. In J. M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp.81-99). London: Paul H Brooks
- Willmes, K. & Deloche, G. (1997). Editorial- Methodological issues in neuropsychological assessment and rehabilitation. *Neuropsychological Rehabilitation*, 7(4), 273-277.

- Wilson, B. A. & Powell, G. E. (1994). Neurological problems: treatment and rehabilitation. In S. J. E. Lindsay & G. E. Powell (Eds.), *The handbook of clinical adult psychology*. 2nd. Ed. (pp. 689-704). London: Routledge.
- Wood, R. L. (1984). Behaviour disorders following severe brain injury: their presentation and psychological management. In N. Brooks (Ed.), *Closed head injury: psychological, social and family consequences* (pp. 195-219). Oxford: Oxford.
- Woolfolk, R. L. (1992). Hermeneutics, social constructivism and other items of intellectual fashion: Intimations for clinical science. *Behaviour Therapy* , **23**, 213-223.
- Workman, J. P. (1995). Using electronic media to support fieldwork in a corporate setting. In R. Hertz & J. B. Imber (Eds.), *Studying elites using qualitative methods*. London: Sage
- Zarski, J. J. & Depompei, R. (1991). Family therapy as applied to head injury. In J. M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 283-297). Baltimore: Paul H. Brooks
- Zasler, N. D. & Kreutzer, J. S. (1991). Family and sexuality after traumatic brain injury. In J. M. Williams & T. Kay (Eds.), *Head injury: a family matter* (pp. 253-270). London: Paul H. Brooks.