

The Psychological Effects of Traumatic Brain Injury on the Quality of life of a Group of Spouses/Partners

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ABSTRACT

This study explored the psychosocial impact of traumatic brain injury on the perceived quality of life of a purposefully selected group of 14 spouses/partners of head injured persons by means of a self-administered questionnaire. Analysis of responses revealed that spouses/partners' altered communication patterns were perceived to have affected interpersonal relationships and quality of life extensively, indicating the need for speech-language therapy. Decreased income was noted due to the low incidence of return to work. Participants reported changes in family relationships, particularly between the injured person and their children as well as deterioration in marital relationships, suggesting the necessity for family therapy and marital counselling. Various emotional reactions were documented in response to injury. Yet most respondents expressed acceptance of their new roles and responsibilities despite the difficulties entailed. Since injured persons were dependent on their spouses/partners to a large extent, most of the latter reported feeling tied down. Loneliness predominated as a social consequence despite the support of pre-injury friendships. In terms of coping resources, friends, family, religion and support groups were perceived to be most effective. Results are discussed in terms of their clinical implications for psychosocial rehabilitation and spouse/partner counselling.

OPSOMMING

Hierdie studie het die psigososiale impak van traumatiese breinbesering op die lewenskwaliteit van 'n spesifiek geselekteerde groep van 14 eggenote/ geselle/ maats van breinbesserde persone ondersoek deur middel van 'n self-toegepaste vraelys. 'n Analise van die uitslae het getoon dat die eggenote / geselle / maats se ervaring van die veranderde kommunikasiepatrone 'n groot invloed op interpersoonlike verhoudinge en lewenskwaliteit gehad het, wat aandui dat spraak-taal terapie nodig is. Verminderde inkomste is opgemerk, as gevolg van die lae hoeveelheid terugkeer werk toe. Deelnemers het veranderinge in familieverhoudinge gerapporteer, veral tussen die beseerde persone en hul kinders, sowel as 'n verswakking in huweliksverhoudinge, wat aandui dat gesinsterapie en huweliksberading nodig is. Verskeie emosionele reaksies is beskryf teenoor die besering. Tog het die meeste respondente aanvaarding van hulle nuwe rolle en verantwoordelikhede uitgedruk, ten spyte van die probleme wat ondervind is. Aangesien die beseerde persone in 'n groot mate van hulle eggenote / geselle / maats afhanklik is, het die meeste deelnemers beskryf dat hulle vasgevang voel. Eensaamheid was die oorwegende sosiale gevolg, ten spyte van die ondersteuning van vriendskappe voor die besering. In terme van bekampingsbronne, is vriende, familie, godsdiens en ondersteuningsgroepe as die mees effektief beskou. Resultate is bespreek in terme van kliniese implikasies vir psigososiale rehabilitasie en eggenoot / geselle-berading.

KEY WORDS: traumatic brain injury, spouses, partners, quality of life

INTRODUCTION

In South Africa, the incidence of traumatic brain injury (TBI), which includes both penetrating injuries from sharp objects as well as closed head injuries from blunt objects is regarded as very high, namely 316 per 100 000 persons (Nell & Brown, 1990). Furthermore, improved medical care has made it increasingly likely that persons with severe head injuries will survive. Unfortunately, a considerable number are likely to remain disabled, placing a burden on their families (McKinlay, Brooks, Bond, Martinage, & Marshall, 1981). Relatively good physical recovery has been found

to occur with most closed head injured patients. However, a significant number remain with psychosocial deficits and/or cognitive impairment (Ponsford, 1995a). After traumatic brain injury, many patients who appear to be functioning normally may have subtle communicative and social problems (Penn, Jones, Schman, Vyncke, Watt, & Fridjhon, 1998). Since these cognitive and behavioural problems may not be immediately visible (Tate, Lulham, Broe, Strettle, & Pfaff, 1989), professionals may be quick to gloss over them, underestimating their impact on the patient's functioning within the family environment.

As early as 1978, Lezak (1988) documented specific reactions experienced by relatives living with chronically disabled brain injured individuals, which included feeling trapped, socially isolated, abandoned by extended family and abused by the patient. Indeed, more than two-thirds of relatives in a study by McKinlay, et al. (1981) felt moderately to severely burdened by mental and behavioural changes in their family member one year after injury. Since then, studies have shown that traumatic brain injury creates an enormous burden on family life which increases rather than decreases over time (Brooks, McKinlay, Symington, Beattie, & Campsie, 1987).

When spouse and parent caregiver responses were compared, spouses consistently reported a greater number of behavioural problems which were perceived to have increased in severity over time (Hall, Karzmark, Stevens, Englander, O'Hare, & Wright, 1994). Interestingly, Panting and Merry (1972), and later, Thomsen (1984), asserted that marital relationships appeared to be less resilient to the effects of strain than parent-child relationships. Oddy, Humphrey and Uttley (1978) found that marital relationships and family life appeared to withstand the changes resulting from brain injury that had occurred six months before. Nonetheless, there is extensive evidence of deterioration or dissolution of marital relationships following traumatic brain injury (Thomsen, 1984). The frequently reported marital, social, financial and emotional difficulties may have a considerable impact on the quality of life of the spouse/partner of a brain-injured individual.

Much emphasis has been placed on the issue of improving quality of life as a realistic goal in rehabilitation (Pain, Dunn, Anderson, Darrah, & Kratochvil, 1998). According to the World Health Organization (1993), quality of life may be defined as the perception of individuals of their positions in life in the culture and value system in which they live, relative to their goals, expectations, standards and concerns. It is said to be a broad ranging concept affected in a complex way by individuals' physical health, psychological state, level of independence, social relationships and their relationships to salient features in their environment (WHO, 1993). This definition encompasses the propositions of those who view quality of life as the impact of a perceived health state on the ability to live a fulfilling life; the affective response to a role situation and the discrepancy between an individual's desired and actual circumstances (Bowling, 1995). However, a shortcoming of this definition is the fact that no mention is made of the link between communication and quality of life.

Many studies have focused on the quality of life and psychosocial functioning of head injured persons (for example: Klonoff, Costa, & Snow, 1986; Tate et al., 1989). Researchers have also investigated aspects of the psychosocial functioning of the relatives of persons who have sustained traumatic brain injury (for example: Thomsen, 1984; Livingston, Brooks, & Bond, 1985; Brooks et al., 1987). Many of the studies assessing the latter have used mood rating or stress rating scales. Indeed, the use of a single measure of burden was evident in a study by Brooks and McKinlay (1983), who found that personality changes following brain injury were associated with high subjective burden in relatives.

Single ratings of burden or stress may be criticized as being superficial and having limited clinical value since they fail to describe the manifestations of strain which require intervention. More detailed studies are necessary to gain knowledge regarding the specific parameters affecting psychosocial adjustment in order to design effective rehabilitation programmes for patients and their families. One such study by Livingston, et al. (1985) investigated the burden of relatives in a more detailed manner, considering aspects of psychiatric and social functioning. Similarly, in their study exploring predictors of burden on caregivers, Brooks, et al. (1987) described parameters such as language and physical dependence. However, although detailed, these studies neglected many factors affecting quality of life such as financial issues, family dynamics and strategies to alleviate burden. In addition, the relatives and caregivers in these studies were not necessarily the spouses / partners of the injured person. A recently published South African study compared the changes in emotion and daily function experienced by a group of partners of brain injured individuals with a group whose partners had experienced spinal cord injuries (Levor & Jansen, 1999). The study explored the stress levels and restrictions of social and sexual life of partners in order to identify the needs and available support for each subgroup. However, as in previous studies, detailed information regarding issues such as financial concerns, family relationships and most importantly, communication was not obtained.

Since quality of life has been defined and operationalized in so many different ways, the present study endeavoured to address weaknesses identified in earlier studies and provide a broader perspective on quality of life of spouses/partners by combining domains such as changes in communication patterns, financial variables, physical, social, emotional and psychological functioning and coping strategies. Quality of life was operationally defined as the contribution and interaction of these particular factors which were selected following consultation with experts in the field, and with a subject who was not included in the final sample, as well as on the basis of extensive reviews of the literature and research on the topic, for example: communication (Wertz, LaPointe & Rosenbek, 1984); financial factors (Bowling, 1995); family relationships (Panting & Merry, 1972); emotional, physical and social factors (Bowling, 1995); and coping (Hall et al., 1994).

Currently in South Africa, there has been a fundamental shift in the way that disabled people are viewed. The emphasis has moved away from the individual medical perspective to the social model which considers the human rights and development of not only those with disabilities, but also of their families (White Paper on an Integrated National Disability Strategy, 1997). Based on this model, the current study sought to discover the effects of brain injury on the spouse/partner and family of the injured person. Insight into the changes in family life, particularly the change in quality of the spouse's/partner's life as a result of traumatic brain injury has direct clinical relevance. Specific communicative, cognitive or behavioural issues which are perceived by spouses/partners to interfere with adaptive family functioning might be targeted in therapy with the brain injured individual, as well as in family or spouse counselling sessions. By understanding family

needs and expectations, staff might be able to provide the appropriate education and support to facilitate the setting and achievement of realistic goals for rehabilitation. It was also anticipated that, as a result of increased knowledge of the factors that appeared to correlate with a richer quality of life, professionals would be better equipped to advise families regarding strategies that might be used to improve their lives.

Communication is a primary ingredient for a favourable quality of life, fulfilling an essential role in the adjustment and psychological well being of humans in their social context (Swindell, Holland, & Reinmuth, 1994). It is thus considered the domain of a speech-language therapist to investigate issues affecting quality of life such as social life, marital relationship and financial independence, many of which rely heavily on intact communication processes. For these reasons, the study endeavoured to investigate the impact of traumatic brain injury on the quality of life of the injured person's spouse/partner. Various psychosocial concerns and perceptions of the spouse/partner that might contribute to quality of life were explored including financial, communication, social and marital factors as well as family functioning and coping mechanisms.

METHODOLOGY

AIM

To investigate the psychosocial impact of traumatic brain injury on the quality of life of spouses/partners living with them.

Sub-aims

In order to address the above aim, the following sub-aims were formulated:

1. To elicit subjects' perceptions regarding the communicative abilities of the individual with TBI which might contribute to psychosocial problems.
2. To obtain information on the perceived impact of the TBI on the occupational status of the injured individual and the financial status of spouses / partners.
3. To explore perceived changes in family dynamics, roles and responsibilities as a result of the TBI.
4. To gauge the perceived influence of the TBI on marital or common law relationships.
5. To determine the perceived emotional effects of the TBI on the individual's spouse/partner.
6. To assess the influence of the TBI on the spouses/partners' social life.
6. To explore coping mechanisms of the subjects surveyed.

RESEARCH DESIGN

An exploratory-descriptive, single group research design, involving the use of a self-administered questionnaire, was employed to investigate the aims of this study. This design was chosen because of the difficulties experienced in recruiting sufficient subjects who met the subject selection criteria, as well as the need for in-depth coverage of a wide range of dimensions thought to impact on quality of life.

SUBJECTS

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Subject selection criteria

Subjects were selected according to the following criteria:

Marital status: Subjects were required to have been married civilly or by common law at the time of the injury as this study focused specifically on partners of persons with TBI.

Type of injury of spouse/partner: Subjects' spouses/partners were required to have sustained a brain injury due to trauma, rather than cerebrovascular accident, where damage is usually more focal and specific than the damage affecting many aspects of physical, cognitive and psychological functioning (Hagen, 1984) that results from acceleration-deceleration injuries.

Time since injury: At least two months had to have passed since the injury to allow the initial shock of the injury as well as many of the patient's cognitive impairments to have passed (Hagen, 1984), giving way to more long-term psychosocial concerns on which this study focused.

Additional disabilities: Subjects were required not to present with any additional known disabilities that might have confounded the results.

Living status: The subjects needed to physically live with the individual with TBI at the time of the study.

Subject selection procedure

The researcher obtained a sample of 33 persons by conducting record reviews of persons with TBI who had been discharged from various rehabilitation hospitals in Johannesburg as well as by approaching a support group for head injured persons and their families, a nursing home for the long-term care of head-injured patients, speech therapists and a neuropsychologist. Although it is acknowledged that non-representative, non-probability, purposive sampling may limit generalisation of the results of the study, it was anticipated that many of the subjects' psychosocial concerns might apply to other persons with TBI who had attended rehabilitation programmes.

Description of subjects

Of the 33 questionnaires that were sent out to potential respondents, 14 were returned, representing an adequate response rate (Babbie, 1995). Demographic information obtained from these 14 subjects is set out in Table 1. The majority of subjects were females. Ages of subjects ranged from 20 to 58 years. Time since injury ranged from between 5 months to 10 years. They had lived with their spouses/partners from between 1 year to 35 years. All of the traumatically brain injured spouses had received speech-language therapy.

RESEARCH INSTRUMENTATION

A self-administered questionnaire was selected as a means of data collection, a copy of which is set out in Appendix A. Original questions were supplemented with items generated from existing scales (Records, 1997), on the basis of research literature (Livingston et al., 1985). The questionnaire was divided into eight sections in order to elicit information on subjects and their spouses/partners as well as obtain data in respect of the seven sub-aims of the study.

Table 1: Demographic Profile of Subjects (N = 14)

	Category	Number of Subjects
Age of subjects	20-25 years	2
	26-30 years	2
	31-35 years	0
	36-40 years	3
	41-45 years	3
	46-50 years	2
	50+ years	2
Gender of subjects	Male	2
	Female	12
Duration of marriage/ living together	1-5 years	3
	6-10 years	3
	11-15 years	1
	16-20 years	1
	21-25 years	4
	26-30 years	1
	31-35 years	1
Age of injured spouse/ partner	26-30 years	2
	31-35 years	2
	36-40 years	2
	41-45 years	4
	46-50 years	2
Number of children	0	1
	1	1
	2	6
	3	3
	4+	3
Time since injury	5-8 months	6
	9-12 months	3
	1-5 years	2
	5-10 years	3

The following sections were thus included:

Demographic Information: This section was aimed at obtaining biographic information about subjects and their spouses/partners. Questions regarding the *ages of subjects* and their *partners/spouses*, *time since the injury*, *number of children*, and *duration of marriage/living together* appeared in this section. It was felt that *time since the injury* implied recovery and should therefore be considered in comparison of results. An additional reason for the inclusion of this factor is that marital functioning has been found to deteriorate with increased time since injury (Livingston et al., 1985). *Duration of marriage/living together* may indicate stability, which would affect the adjustment of spouse/partner to injury.

Communication: The onset of a major communication disorder in a married adult frequently has a profound effect on the spouse/partner and the couple's relationship (Rollin, 1988). As such, a section of the questionnaire was dedicated to communication and incorporated a checklist of dysfunctional linguistic patterns found after TBI including vague, tangential language, word finding difficulties and problems

experienced in distracting environments (Snow & Ponsford, 1995). These deficits comprised some of the items on the checklist comparing patients' premorbid and postmorbid communication patterns. Efforts were made to use terms that could be easily understood by lay persons; however, it is still possible that subjects may have assigned different interpretations to those intended. Severity of language dysfunction was not assessed; nor were subjects asked to indicate which communication impairments they regarded as most or least important. Question 1 elicited details regarding the speech of the injured person since speech problems resulting from a traumatic brain injury may contribute to decreased quality of communication (Ponsford, 1995a). Question 2 dealt with the communicative burden placed on the uninjured spouse/partner and question 3 with the sensitivity of the person with TBI to interlocutors in general. An open-ended question was asked regarding the overall effects of altered communication patterns on the relationship in order to elicit individual expression of feelings.

Occupation and Finance: Financial strain has been documented as a consequence of traumatic brain injury. TBI has also been found to have an adverse, long-term impact on employment and productivity (Hall et al., 1994). Thus, questions in this section dealt with past and present occupational status of both the injured spouse/partner and the subject. In addition, since financial concerns tend to affect quality of life (Bowling, 1995), subjects were asked to compare their premorbid with their present income and standard of living.

Family Life: Following brain injury, there is likely to be a significant disruption of premorbid roles and relationships within the immediate family as well as with parents-in-law (Ponsford, 1995b). Consequently, this section explored the relationship between subjects and their spouse/partner's family; the family's reactions to the individual with TBI; familial visits; the distancing or bonding effects of the injury as well as the changed responsibilities. In addition, subjects were asked to rate their spouses/partners on a five point scale according to their abilities to perform various activities of daily living since functional recovery of patients has been related to family adjustment (McKinlay et al., 1981).

Marital Relationship: Evidence in support of the stresses placed on marital relationships by traumatic brain injury comes from the figures for divorce after brain injury: Seven of the nine severely brain injured married patients, whom Thomsen (1984) followed up ten-to-fifteen years post-injury, had been divorced. Questions in this section were based on factors found by previous studies (such as Panting & Merry, 1972) to affect marital relationships. Areas that were assessed included: the frequency of arguments since the injury, acceptance of the spouse/partner's limits, consideration of divorce, satisfaction with the marriage, ability of the spouse/partner to fulfil the subjects' emotional needs and the strength of the marital relationship.

Emotional Aspects: In this section spouses/partners were asked about their personalities prior to the injury since the past illness experience, whether psychiatric or medical, of relatives of persons who have suffered brain injury has been found to be highly predictive of their psychosocial breakdown. Many of the deficits associated with brain injury preclude individuals' functioning and self-sufficiency, making them dependent on family members for financial support, transport and decision-making. Lack of independence often places a burden on family members and interferes with their quality of life (Livingston, 1987). Thus, two questions assessed the dependence of injured spouses/partners on subjects and the effects thereof. Subjects were also asked whether their own health had suffered as a result of the injury, since physical health has been implicated as a contributor to a good quality of life (Bowling, 1995). Readjustment of the spouse's/partner's personal schedule is often necessitated by TBI to allow for the assumption of new responsibilities or caring for the injured person and may detract from the quality of life of the subject. Thus, a question regarding the cancellation of personal plans was included at the end of this section.

Social Life: Loss of friends and social isolation are commonly associated with chronic illness or disability and may impact on quality of life (Bowling, 1995). For this reason, questions assessing social isolation and

interaction, as well as satisfaction with social life were included.

Coping Resources: Resources such as support groups, case management, medication, recreational activities and respite care have been proposed as potential avenues to relieve the burden of family members and improve quality of life (Hall et al, 1994). The extent to which these factors had been of assistance to subjects in coping with the stresses of the injury was tapped in this section. Responses were considered important since it was anticipated that they would provide practical suggestions for improving quality of life, which was one of the aims of the study.

PROCEDURE

Pre-testing the questionnaire

As mentioned previously, the research instrument was based on an extensive literature review and early drafts were scrutinized by an expert in the field of TBI (de Picciotto, 2000) in order to enhance content validity. Efforts to improve the reliability of the questionnaire included consultation with a statistician known to have extensive experience in questionnaire construction, as well as pre-testing the research tool on a subject who met the subject selection criteria but was not included in the final study. These procedures were designed to assess applicability and practicality of questions. Following the pre-test, ambiguous questions were adjusted and the items finely tuned.

DATA COLLECTION

Upon subjects' agreement to participate in the study, arrangements were made for them to receive, complete and return the hand delivered questionnaire. An Information Sheet set out in Appendix A, explained the purpose of the research project, assured subjects that their anonymity would be respected, provided a contact name and telephone number in the event of the person having any queries, and included a commitment by the researchers to report back the results of the study to participating subjects.

DATA ANALYSIS

Data were analysed using descriptive statistics in the form of frequency counts and percentages illustrated via a variety of tables and figures.

RESULTS AND DISCUSSION

Results are presented in accordance with the sub-aims of the study.

PERCEPTIONS REGARDING THE COMMUNICATIVE ABILITIES OF THE INDIVIDUAL WITH TBI

Figure 1 depicts the distribution of language problems that were reported by the sample.

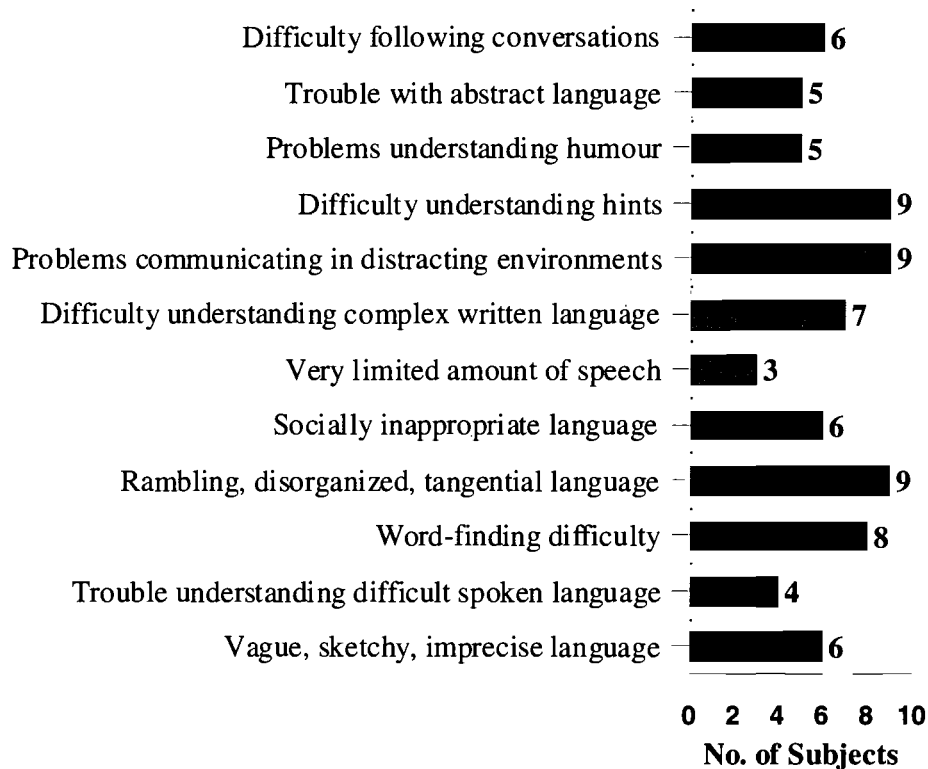
As evident from Figure 1, *disorganized, rambling, tangential language* was reported by 9 of the 14 subjects. Ylvisaker and Szekeres (1996) suggest that rambling discourse may result from the impaired executive functioning, attentional processes and organizational skills that are characteristic of prefrontal injury. Since

many of the language patterns associated with TBI have been linked to underlying cognitive dysfunction, it has been suggested that speech-language therapists work within a cognitive-communicative framework of intervention (Ylvisaker & Szekeres, 1996). Moreover, spouses/partners should be informed about the basis for the communicative difficulties which invariably disrupt conversation and hence, interpersonal relationships, in order to assist their coming to terms with the frustration experienced when conversing with their apparently insensitive partners.

Deficits in selective attention (Snow & Ponsford, 1995), as well as a difficulty with the figure-ground

processing of salient auditory information may have been responsible for the perception of 9 out of 14 subjects, that their injured spouses/partners experienced *problems communicating in environments that were full of distractions*. One may speculate that this limitation probably affected the subjects' quality of life since it implied a reduced number of locations in which meaningful social or communicative interactions might take place. In places where it is impractical to manipulate the environment in order to facilitate conversation with the injured person, spouses/partners may be forced to avoid communication completely, thereby limiting opportunities for social interaction in the outside world.

Fig. 1 Changes in language patterns as perceived by the spouses/partners of individuals with TBI post-injury (N=14)



Of the 14 subjects, 9 noted that their injured spouses/partners had *difficulty understanding hints*. This problem might have resulted from deficits in reasoning ability, which has been defined by Ylvisaker and Szekeres (1996, p.549) as "the process of considering evidence and making inferences or drawing conclusions". The inability to understand hints may lead to frustration of spouses/partners at having to spell out all their requests directly. Conveying information directly may not always be appropriate such as when speaking in front of children or in company. In addition, when the subtleties of sexual innuendo are not understood, deterioration in intimate relationships may result (Ylvisaker & Szekeres, 1996).

Word finding difficulty, which 8 out of 14 subjects reported, was also documented by Thomsen (1975) as

one of the more common linguistic problem following head injury. When the speaker has word retrieval difficulties, there may be an increased burden on the interlocutor, such that he/she must guess the intended words, encourage circumlocution or endure the frustration and helplessness of seeing the speaker struggling to express him/herself.

Six subjects reported *vague, sketchy and imprecise language*, which may have been caused by listener insensitivity or word retrieval problems. It is likely that this linguistic pattern may be a source of frustration for the interlocutor who may experience difficulty comprehending the injured person's message.

Six of the 14 subjects characterized the language of their injured spouses/partners as being *socially*

inappropriate. Indeed, inattention to social context resulting in socially inappropriate behaviour and verbal 'dysdecorum' has been described as associated with prefrontal damage (Alexander, Benson & Stuss, 1989). For example, one subject commented, "When in company, his communication is totally unacceptable. The things he says embarrasses everyone, including me." Withdrawal from social situations and public gatherings may result from such embarrassment. Spouses/partners may also have to endure verbal abuse, which might decrease their self-esteem and quality of life.

Of the 14 subjects, 6 perceived that their spouses/partners had *difficulty following conversations*; whilst 4 reported that their spouses/partners had *trouble understanding difficult spoken language*. Presumably, such deficits might manifest in a loss of interest of injured persons when their spouses/partners attempt to discuss problems of daily living or issues in their relationship. Thus the quality and quantity of interaction could be adversely affected.

Five out of the 14 subjects noted that their injured spouses/partners had *problems understanding humour*. Comprehension of humour has been attributed to the ability to think abstractly, a capacity that is frequently damaged as a result of brain injury (Hartley, 1995). If one member of a couple cannot appreciate humour, their relationship may lack a means by which to release tension in order to alleviate the gravity of the situation.

When asked to elaborate on their spouse/partner's communication problems in response to the open-ended item, subjects mentioned *lack of eye contact, motor speech difficulties*, and *speech that was either too soft, too slow or dysfluent*. In addition, eight subjects reported that they *sometimes* found communication with their partners/spouses to be tiring. Whilst four noted that communication was *often* tiring, only one subject reported *never* finding communication tiring. The fact that all but one subject found communication with their spouses/partners to be tiring seemed to highlight the communicative burden placed on the interlocutor by injury-related communication problems. This result may indicate use of ineffective communication techniques, a problem that perhaps should receive more prominence as an intervention goal of speech-language therapists. The concentration required to guess the message of the person with TBI as well as the effort required to explain or rephrase to ensure the comprehension of an injured spouse/partner might induce fatigue or despair. As a result, spouses/partners might refrain from discussing their concerns with the individual with TBI, causing emotional burdens and stress to accumulate, not having had an opportunity to be expressed. Persons with TBI, too, might be given fewer opportunities to express their own problems, causing frustration and aggression. The egocentricity (Lezak, 1988), rigidity and lack of insight (Giles & Clark-Wilson, 1993) that have been reported as sequelae of brain injury, might cause individuals with brain injury to demonstrate an inability to adapt to their conversational partners. In the current study, perceptions of the injured spouses/partners' *sensitivity to the listener* were gauged with reference to these particular manifestations. Eight subjects reported that their spouses/partners rephrased, explained or repeated information when the listener failed to understand them. However, 6 injured persons were reported not to

demonstrate such sensitivity. In addition, 10 out of the 13 individuals who answered the question reported that their spouse/partners tended to overestimate or underestimate the listener's knowledge of the subject being discussed. As may have been expected, given the above-mentioned results indicating decreased listener sensitivity, all but 2 subjects reported that communication tended to break down between themselves and their spouses/partners. Of these, half reported that breakdown occurred often; whilst the other half noted that breakdown only occurred sometimes. Frequent conversational breakdown may cause a great deal of frustration and resentment to the communicatively impaired individual, who is often unaware of his/her deficits (Snow & Ponsford, 1995), as well as for the interlocutor.

Twelve of the 14 subjects reported that their injured spouses/partners with TBI often misinterpreted what they had said to them. If frequent *breakdown or misinterpretation* of communication is used as a measure of quality of life, then brain injury with its effects on communication may be said to have detracted from the quality of life of 12 of the 14 spouses/partners.

Many relationship breakdowns have been attributed to faulty communication, even without the added burden of a neurogenic communication disorder (LaPointe, 1999). In the face of the many expressive and receptive language difficulties that have been associated with traumatic brain injury, relationships are even more likely to be at risk. Nine out of the 14 subjects in the current study affirmed that their spouse/partners' *altered communication had affected their relationship in some way*. Verbatim quotes set out in Table 4 starkly reflect the impact on sexual relationships, communication, roles and personality.

In summary, a wide variety of communicative impairments were found to have detracted from the quality of life of most subjects in the current study, and appeared to suggest the need for speech-language therapists to assist couples to find more effective ways of communicating.

IMPACT OF INJURY ON THE OCCUPATIONAL STATUS OF THE PERSON WITH TBI AND THE FINANCIAL STATUS OF SPOUSES/PARTNERS:

The current study found that of the 14 brain injured persons who were reported by their spouses/partners to have been employed full-time prior to the injury, 10 had not returned to work at all, 2 worked part-time, 1 ran errands for his spouse at work, and 1 was employed in a different capacity. These results are in line with the research literature which confirms that TBI often results in cognitive, physical, psychological or communicative deficits, which may preclude the injured person's return to work. Return to work statistics range from 3% to 100% depending on the severity and sequelae of the injury, the demands of the job as well as a multitude of other factors (Penn et al., 1998).

Furthermore, economic issues relating to medical treatment, rehabilitation, earnings loss and caregiver role adjustment may create enormous concerns for individuals and families in health care crises (LaPointe, 1999). In the current study, 9 subjects indicated that their income had dropped significantly since the injury, 2 stated that their income had dropped slightly while only 3 subjects

commented that their income had remained the same as it had been prior to the injury. These findings suggest that in the majority of cases, TBI had impacted on quality of life.

The World Health Organization (1993) related quality of life to the individual's perceptions of his/her position in life in relation to his/her goals, standards and expectations. As such, *satisfaction with standard of living* may be said to impact extensively on perceived quality of life. In the current study, the number of subjects who expressed satisfaction with present standards of living compared to pre-injury standards was equal to the number of subjects who expressed dissatisfaction. This finding seemed to indicate spouses/partners' adjustment and adaptation to the decreased financial status as a consequence of brain injury on the part of those subjects who reported feelings of satisfaction with living standards. However, a weakness of the research project was that self-administered questionnaires did not facilitate further probing of individual items.

Table 2: Perceived effects of injury on children (N=11)

Themes	Quotes
Children's fear of parent with TBI	<ul style="list-style-type: none"> • He has very little patience with children and they have become wary of him, sometimes even scared. • Children are too scared to talk to him because he does not understand when they are joking and when they are serious. • Most of the children (mine) are nervous of him.
Injured parent's reaction to children	<ul style="list-style-type: none"> • He has very little patience with children. • Lost his love and relationship with children. Very formal and irritable with children. • Takes very little interest in the children.
Roles/responsibilities of children	<ul style="list-style-type: none"> • Elder son grew up quickly - emotionally played father roles. • New roles had to be filled by children. They are not as carefree as other kids. • Due to decreased finances had to let maid go, so children have to help around house.

The loss of a child's relationship with one parent may have the impact of draining the emotional resources of the uninjured parent. The latter might feel it necessary to devote more attention, time and love to the child at the expense of his or her own needs and quality of life. Consequently, counselling of children and parents may ease the burden that the changes in family dynamics have imposed.

In the current study, 13 of the 14 subjects expressed the view that their *relationships with their spouse/partner's family* had changed since the injury. In general, the injury was perceived by 6 subjects to have brought family members closer. Three subjects did not perceive any effect on family cohesion. However, 4 subjects stated that the injury had caused negative changes in the form of friction and decreased support and had estranged family members. Mauss-Clum and Ryan

CHANGES IN FAMILY DYNAMICS, ROLES AND RESPONSIBILITIES:

The majority i.e. 13 of the 14 subjects affirmed that there had been a change in their family relationships since their spouse/partner's injury. This finding is in accordance with family systems theory, which views the family as a homeostatic entity where each unit is dependent on every other. As such, a traumatic brain injury sustained by one member is likely to cause a disturbance in the equilibrium of the entire family.

Upon analysis of the comments of participants regarding *changes in their family relationships*, deterioration of relationships with children emerged as a common theme. Examples of subjects' comments regarding the effects of the injury on children may be seen in Table 2.

(1981) pointed out that there tended to be conflict between the uninjured spouse and his or her in-laws. They explained that parents might see their role as protecting their child from the possibility of divorce and were likely to become possessive and jealous. Decreased contact with immediate and extended family members might also have resulted from friction caused by reversal of roles or the family's discomfort with behavioural, communicative or cognitive changes. In this respect, Rosin (1977) noted disengagement to be a method of dealing with the brain injury of a relative. In the process, family and friends might be neglected due to lack of time following the spouses/partners' assumption of additional responsibilities (Boisclair-Papillon, 1993). Friends might also feel uncomfortable or awkward in the presence of the brain-injured person and decrease their contact with the spouse/partner too as a result.

However, although infrequent visiting and avoidance of the injured person might help the extended family to adjust to the effects of the injury, spouses/partners of the injured person may experience isolation and a lack of support due to the reduction in family contact. It is of interest that 8 subjects in the present study reported that the *extended family*, including aunts, uncles and cousins, tended to visit as often as they did before the injury. Likewise, 7 subjects mentioned that the *immediate family* tended to visit as frequently as previously, while one subject reported that visits were more frequent following

the injury. Frequent visiting may indicate the presence of family support and adjustment to the injury. In order to foster increased understanding, spouses/partners should be provided with the emotional support as well as the information needed to explain the consequences of the injury to the injured person's family.

In order to gain a better understanding of the extent to which roles had shifted since the injury, the current study required subjects to indicate the person responsible for various tasks before and after the injury.

Table 3: Responsibility for various tasks pre and post-injury

Task	Pre-injury			Post-injury		
	Self	Spouse/ partner with TBI	Both	Self	Spouse/ partner with TBI	Both
Caring for children (n=8)	5	2	1	7	0	1
Dealing with medical aid & social agencies (n=10)	5	4	1	10	0	0
Running household (n=10)	6	2	2	9	0	1
Making financial decisions (n=10)	1	5	4	9	1	0
Providing main source of income (n=10)	3	4	3	7	3	0

Numbers in the different categories do not total 14 as not all tasks were applicable to all subjects.

Table 3 shows that where the responsibility of caring for children had previously been that of the spouse/partner who had sustained the injury, it was now shared and where it had been a shared duty, the role had been assumed by the uninjured spouse/partner. The relinquishment by many of the injured persons of tasks such as dealing with medical aid and social agencies, running the household, making financial decisions, and being the main source of income, is understandable if one considers that injury to the frontal lobes of the brain tends to impair executive functioning including planning, problem solving, judgement and decision-making (Ponsford, 1995a).

Upon analysis of the reactions of subjects to role changes, most appeared to have accepted their additional responsibilities. Only two subjects admitted to feeling angry or uncertain as a result of having to undertake new responsibilities. Others appeared to acknowledge the difficulties, yet expressed acceptance of their lot. These results provide support for the literature which states that role reversal may impact extensively on the quality of life of the uninjured spouses/partners upon whom additional new roles and responsibilities are suddenly thrust (LaPointe, 1999).

PERCEIVED INFLUENCE OF INJURY ON MARITAL/Common LAW RELATIONSHIPS:

Table 4 shows the subjects' extent of agreement or disagreement with various statements regarding the perceived influence of the injury on marital or common law relationships.

Half of the current sample reported that their *relationship with their spouse/partner had deteriorated with the passage of time since the injury*. However, although the small number of subjects precluded the computing of correlations, the time since injury did not appear to affect perceptions of marital decline. Deterioration in marital relationships was noted by those whose spouses/partners had sustained the injury 5-10 years before as well as by those who had been injured between 5-12 months previously. However, 6 other subjects whose spouses/partners' injury had occurred between 1-5 years before as well as 5-8 months before, failed to report such a decline. In terms of the literature, marital functioning was noted to have decreased between 3 and 6 months post-injury in a study by Livingston, Brooks and Bond (1985).

Duration of marriage also did not appear to influence the perception of marital decline over time as couples who had been married for 1 year, 6 years, 25 years and 28 years reported decline, while others with marriages of 7, 16 and 34 years duration failed to report deterioration. Nevertheless, since half the subjects reported that they perceived their marriages to have deteriorated over time, referrals for marital counselling, guidance regarding future expectations, and long-term coping strategies may

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need to be made available in an effort to conserve marriages and increase the quality of life of both partners.

In the current study, 5 of the 7 subjects noted that their injured spouse/partner had become more aggressive and also reported more arguments since the injury. Increased aggression and irritability are commonly reported personality changes following brain injury (Giles and Clark-Wilson, 1993) and might lead to an *increase in arguments*. Eight subjects stated that they *had not considered divorce*. Lezak (1988) explains that feelings of responsibility, past gratitude to the spouse, guilt, and fears of social rejection might make it difficult

to initiate separation or divorce procedures. Results from the present study may also indicate that subjects had resigned themselves to their new roles, having managed to accept and adjust to changes in their spouses/partners. Indeed, 10 subjects admitted that they had *accepted their spouses/partners' limits*. In addition, the possibility of subjects furnishing 'socially desirable' responses to these very sensitive items cannot be discounted, and leaves the validity of this item open to question (Rosnow & Rosenthal, 1996). It is also possible that it was too early post-injury for respondents to assess the long-term effects of the injury on the marital relationship.

Table 4: Perceived influence of injury on marital/common law relationship

<i>Statement</i>	Strongly Agree/agree	Neutral	Disagree/ Strongly Disagree
Our marital relationship has not changed despite the injury	10	1	3
My relationship with my spouse/partner has deteriorated as time has passed since the injury	7	1	6
I accept my spouse/partner's limits	10	2	2
I have considered divorce	3	No response	8
I feel as though I am married to a stranger since the injury	7	5	2
I have a close, confiding relationship with my spouse/partner	4	4	6
I keep my frustration inside myself	11	1	2
I am satisfied with my marriage	5	2	7
My spouse/partner can no longer fulfill my emotional needs adequately	10	3	1
We argue more now than we did before the injury	7	3	7

Note: Responses from the 5-point rating scale were collapsed to form three categories. N=14

Eleven subjects reported that they tended to *keep their frustration inside themselves*. The effect of a build-up of inner frustration has been shown to exert an adverse effect on people's physical and mental health (Burnard, 1991). Hence, rehabilitation personnel should be made aware that spouses/partners might appear from the outside to be coping with their roles and their spouse/partner's deficits. However, internally, they might harbour much anxiety and frustration that needs to be expressed and addressed.

Half of the subjects in the current study agreed with the statement "I feel as though I am married to a stranger since the injury". In this respect, the personality change that results from brain injury has been reported to be most difficult for spouses/partners to deal with (McKinlay et al., 1981; Thomsen, 1984) presumably since it alters the dynamics and fulfilment of needs within the relationship. The high number of neutral or uncertain replies to this item may have been due to a 'central tendency response set' whereby subjects tend to choose the central response options rather than committing themselves to a definite agree or disagree response

Only 6 of the 14 subjects reported not having a *close, confiding relationship with their injured spouse/partner*. The fact that so few relationships were said to be close

and confiding might indicate the need for marriage counselling of persons with TBI and their spouses/partners.

Ten subjects in the current study reported that their injured spouses/partners were unable to *fulfil their emotional needs adequately*. This phenomenon may be explained by the fact that because brain injured spouses/partners often tend to be childish, self-centred and irritable, they are unable to provide the emotional support that had formed an integral part of their relationships prior to the injury (Mauss-Clum & Ryan, 1981). According to Lezak (1988), spouses may suffer the loss of a relationship that satisfies even the most basic expectations of a marriage.

One subject in the present study remarked that her husband who used to be her "best friend and lover" had now become no more than a "child-like companion." Half of the subjects in the current sample asserted that they were not satisfied with their marriages, probably indicating a perceived reduced quality of life. However, 5 subjects expressed marital satisfaction despite the injury, suggesting positive adjustment as well as a satisfactory quality of life. It is also possible that the 'central tendency response set' was operating, whereby subjects responded similarly to various items (Rosnow & Rosenthal, 1996).

Subjects were asked to describe changes in the spouse/partner post-injury which had exerted the most impact on the relationship. Analysis of the verbatim

responses of subjects revealed certain common themes which are highlighted in Table 5.

Table 5: Changes in spouse/partner with TBI that had exerted the most impact on the marital/common-law relationship (N=11)

Themes	Quotes
Loss of sexual relationship	<ul style="list-style-type: none"> • He is constantly insecure because we do not have an intimate sex life. His brain cannot function in that way yet. I accept that. I have become very sympathetic. • I have lost my best friend and lover. We don't have fun anymore. We don't have sex anymore and I am very wary of confiding in him. • No love life. • Between him and myself, he is just the patient and I am the caregiver / provider /decision-maker. There is no other aspect to the relationship.
Communication changes	<ul style="list-style-type: none"> • No communication • We also can't communicate as well as we used to.
Personality changes: blunted emotion, increased aggression	<ul style="list-style-type: none"> • Lack of emotion; increased aggression; onset of depression / negativism • His changed personality. He is quite aggressive now and it's like living on the edge of a volcano. • He is a different person. His personality has changed. • He is also very unemotional in positive loving ways. • He was also a very loving, touchy person. This has all gone. Not only did we live together, play together etc., we also worked together in the same company, different departments. • Loss of intellectual ability and confidence
Role change	<ul style="list-style-type: none"> • I have become the senior partner in running things which he is too proud to feel comfortable with. • The fact that he is not able to help with fetching and carrying of kids. • Changes in roles.
Separation	<ul style="list-style-type: none"> • The fact that he had been in and out of hospital has had a dramatic impact on our relationship.

The profound effect of traumatic brain injury on the marital relationship is reflected in the statement by one of the subjects: "Between him and myself, he is just the patient and I am the caregiver/provider/ decision-maker. There is no other aspect to the relationship." Many subjects mentioned the loss of the sexual relationship. Communication changes and role shifts were also reported to have affected the marital relationship as well as personality changes, particularly blunted emotion. These results appear to be in line with the findings of Tate et al. (1989) who conducted a follow-up study six years post-injury, and found that marital breakdown had occurred in 63% of marriages in the group of brain injured persons with moderate to severe brain injury and in 42% of those with good outcomes.

PERCEIVED EMOTIONAL EFFECTS OF INJURY ON SPOUSE/PARTNER:

The occurrence of traumatic brain injury creates an immediate crisis for relatives, disrupting established relationships, roles, expectations and goals within the family unit (Ponsford, 1995b). However, the crisis is often ongoing since character changes, altered communication patterns and cognitive limitations tend to be of a permanent nature. The advent of brain injury may

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be said to mark the beginning of the spouse/partner's ride on an emotional roller-coaster.

Eight subjects in the current study appeared to deny the permanence of their spouse/partner's disability by reporting that they lived with the *hope* that their spouse/partner would *wake up and return to his/her pre-injury self*. The remaining 6 subjects did not appear to have such unrealistic expectations. However, one stated that she expected her spouse/partner to recover slowly. Based on extensive contact with 13 families of severely head injured patients, Romano (1974) observed denial to be a powerful tool used to come to terms with sudden disability, one of the manifestations of which was the tendency towards fantasies. The tendency towards unrealistic expectations must be considered by rehabilitation personnel when working with spouses/partners, who might resist attempts at the rehabilitation of the injured person (Ponsford, 1995b) or even blame therapists for the failure of the person to return to premorbid capabilities.

Livingston (1987) found that the post-injury adjustment of relatives correlated with their previous psychiatric and medical history. Spouses/partners were thus asked to describe their personalities before the injury. Ten subjects considered themselves to have been *independent*, and 9 said that they had been *easy-going*. These traits probably assisted greatly in the assumption of new responsibilities following the injury. Eleven considered themselves *sociable*, perhaps implying a large framework of social support, or perhaps frustration in the event of social isolation.

In terms of their reactions to their relative's disabilities, Lezak (1988) pointed out the potential of relatives to become deeply conflicted between feelings of responsibility, anger and frustration, and hope for the recovery of the injured person, making them prone to depression. The emotional devastation felt by one of the subjects in the current study was poignantly expressed in the following statement: "All the changes in my husband have frightened and shocked me. I find myself lying about how things are just to keep the peace - somewhere in this mess I lost me!" Current findings showed neither *anger* nor *irritability* to be very prevalent, with only 5 out of the 12 subjects reporting these emotional reactions following the injury. *Sadness* was reported by ten

subjects and the same number noted that their spouse/partner's disability had caused them to feel *burnt out*, possibly as a result of role overload. Eleven of the 12 subjects who responded to this item in the current study noted that they felt *frustrated* as a result of their spouse/partner's disabilities and one subject reported feeling *helpless*. Consequently, it is important that rehabilitation personnel and counsellors advise spouses/partners that negative emotions tend to be a natural consequence of disruption to life and marital relationships.

Notwithstanding the prevalence of negative emotions, feelings of *acceptance* were noted by 11 subjects in the current study, as was the case in relation to role changes explored in the third sub-aim. It is possible that subjects might have accepted the presence of disability intellectually. Yet, in reality, on an emotional level, they may have experienced conflict and burdens resulting in frustration, anger and irritability. Since anguish, fatigue and depression drain the spouse/partner of availability, patience and inventiveness, counselling of the spouse/partner is likely to have a positive effect on both the injured person as well as the entire family.

The *dependence* of injured persons on their spouses/partners for activities of daily living may impact on the spouses/partners' perceived quality of life. Indeed, 6 subjects in the current study noted that they felt tied down to a great extent by their spouse/partners' dependence on them. Another 6 stated that dependence caused them to feel somewhat lacking in independence. Only 2 subjects commented that they did not feel tied down at all despite their spouses/partners' dependence.

In terms of dependence/independence, several factors were considered, namely, transport, decision-making, finance, and communication with unfamiliar people. Results are reflected in Table 6. The finding that only 3 spouses/partners were completely independent in relation to *transport*, was not surprising considering that only one subject reported that her/his spouse/partner was able to drive well. However, in hindsight, it would seem that the terms describing driving ability were not adequately defined, for example, did average driving ability imply ability to drive independently? A further shortcoming of the study was that aspects such as decision-making and finances were not probed further.

Table 6: Extent of dependence of injured spouse/partner on respondents (N=4)

Factors	Totally Dependent	Partially Dependent	Completely Independent
Transport	6	5	3
Decision-making	9	5	0
Finances	10	3	0
Communication with unfamiliar people	8	4	2

The effects of having to care for a spouse/partner as a parent cares for a child may increase the resentment and difficulties involved in care giving. Provision of practical advice to increase the spouse/partner's perceptions of freedom might assist them to cope better both psychologically and physically. By hiring a driver, the person with TBI might become independent in terms of transport. Referral to a financial consultant for financial counselling and advice might assist the uninjured

spouse/partner to meet the challenge of financial planning and decision-making with more confidence and skill. Speech-language therapy might equip the person with TBI to regain independence in the domain of communication.

Ten out of the 14 subjects reported that their *physical health* had suffered in some way as a result of the stress of their partner/spouse's brain injury. This result is not surprising since family members tend to put

aside their own interests and needs to give maximal support to the injured person. Such sacrifice cannot be sustained without a significant physical or emotional toll (Ponsford, 1995b). It is therefore critical that spouses/partners be cautioned by rehabilitation workers to take time out for themselves to maintain their efficiency as caregivers and their quality of life.

The *postponement or cancellation of personal plans* as a result of their spouse/partners' injury was reported by 11 of the 14 subjects in the current study. Ironically, many of the uninjured subjects experienced a degree of handicap, being unable to conduct their lives in accordance with their desired plans. However, whether they resented this postponement or merely accepted it as a fact, is open to speculation. According to LaPointe (1999), health care professionals may fail to recognize the magnitude of the challenge of compromise that is involved in adapting to the new demands that necessitate a change of lifestyle. Perceptions of a disappointing quality of life might cause the build-up of frustration and resentment, which might be expressed as anger towards the injured person or inadequate fulfilment of responsibilities. Rehabilitation personnel and other family members should thus encourage the spouse/partner to accomplish their personal plans where possible and to develop their own interests. In addition,

counselling of spouses/partners by therapists or psychologists should be encouraged in order to help them to express and work through the emotional and psychological impact of the injury.

INFLUENCE OF SOCIAL ASPECTS ON QUALITY OF LIFE

Table 7 illustrates the effects of the injury on subjects' social life. With regard to the *loss of friends*, it is not clear how long after the TBI this loss occurred and needs to be researched in greater depth than allowed by the current study. Although socially inappropriate language was only reported by 6 subjects (as discussed under the first sub-aim), 7 subjects noted that they experienced *discomfort in social situations* since their spouses/partners tended to *say the wrong things at the wrong times*. This finding is understandable if one considers that pragmatic impairment is a major component of language impairment in TBI (Alexander, Benson & Stuss, 1989). In addition, it was not surprising that 5 subjects mentioned feeling embarrassed as a result of their injured spouse/partner's *behaviour in company*. Interestingly, however, only 3 subjects admitted that they tended to *avoid social contact*.

Table 7: Perceived effects of the injury on respondents' social life (N=14)

Statement	Yes	No
I often feel lonely.	11	3
I feel responsible for meeting the social needs of my spouse/partner.	11	3
I feel that I have lost many friends since the injury.	5	9
I have made many new friends since the injury.	4	10
I avoid social contact.	3	11
I am embarrassed by my spouse/partner's behaviour in company.	5	9
My spouse/partner says the wrong things at the wrong time causing me discomfort in social situations.	7	7

The majority of subjects in the current study felt *responsible for meeting the social needs of their injured spouses/partners with TBI*. By increasing their involvement with the injured person, spouses/partners might have less time to devote to the maintenance of their previous friendships. This finding is in line with the results obtained by Kozloff (1987) who studied 37 persons with severe brain injuries and their families. This researcher found that relatives attempted to compensate for the patients' psychosocial inadequacies by expanding their involvement with the patients themselves. The fact that 11 of the 14 subjects also reported that they frequently experienced feelings of *loneliness*, could possibly be due to decreased time for social arrangements or estrangement from friends and from the spouse/partner. One subject affirmed this explanation saying "All our friends don't like to mix in as I am now considered a threat (so called)". It is likely that the loss of

the companionship, guidance and support of a spouse/partner might be the greatest source of loneliness as one subject commented: "I have lost my best friend and lover...I am very wary of confiding in him." Consequently, the fostering of both new and old friendships, as well as membership of support groups should be encouraged on the basis that a larger social circle is likely to ultimately lead to an increase in emotional support and quality of life.

No definitive trends emerged regarding the *satisfaction* of subjects with their present *social life* in comparison with their social life before the injury since responses were evenly distributed along the continuum. Six subjects expressed satisfaction with their present social life, 2 remained neutral and 6 others reported dissatisfaction. Nonetheless, rehabilitation personnel should be aware of the potential for decreased social opportunities to impact negatively on spouses/partners'

quality of life. Where necessary, counselling should be provided to assist individuals to deal with their frustrations. Furthermore, spouses/partners and their families should be encouraged to seek additional opportunities for socialization, particularly, given the broad base of evidence that social support buffers the deleterious effects of stress and anxiety and contributes to psychological well-being (LaPointe, 1999).

EXPLORATION OF COPING MECHANISMS

Subjects were asked to assess the degree to which certain factors had helped them to cope with the consequences of traumatic brain injury in their spouse/partner. Results are summarized in Table 8.

The finding that 5 subjects had not received any form of *psychological counselling* suggested under-utilization of such services which could have been due to any number of reasons, including lack of access, the costs involved, as well as the stigma still associated by some people with this type of therapy. This finding also suggested the need for speech-language therapists to incorporate spouse/partner counselling into any therapy programme so that significant others who are not in contact with other professionals, may receive the necessary emotional support. Ideally, psychological counselling provides an opportunity for the spouses/partners of persons with TBI to work through their emotional responses and to raise practical problems (Ponsford, 1995b).

Table 8: Extent of helpfulness of coping resources (N=14)

Coping Resource	Very helpful	Somewhat helpful	Not at all helpful	Not Applicable
Psychological counselling	2	5	3	4
Religion	8	3	3	0
Support groups	5	2	2	5
Domestic help	5	6	1	2
Friends	10	2	2	0
Medication	4	5	3	2

The fact that a relatively large proportion of subjects felt that *religion* had helped them to come to terms with the devastation of TBI, is understandable if one considers that under such conditions, some people may adopt a philosophical outlook, searching life for meaning and

exploring the significance of their existence relative to a Higher Being. While half the subjects reported that *support groups* had been either very helpful or somewhat helpful, it is of concern that 5 persons had either not had access to or had not made use of such services.

Table 9: Coping strategies perceived as most effective (N=12)*

Themes	Quotes
Friends	<ul style="list-style-type: none"> Support and good friends who listened, cooked or spent time with my husband. Caring friends
Family	<ul style="list-style-type: none"> Family and friends' assistance and support My children, sister, brother-in-law Plenty of family support and support from my spouse
Religion	<ul style="list-style-type: none"> Prayer Faith in God supportive church
Medication	<ul style="list-style-type: none"> Medication for depression
Inner strength	<ul style="list-style-type: none"> My strong personality and determination to succeed and I kept saying to myself * I'll get you, you **** before I really understood his problem. Then I had to swim or sink and I wasn't prepared to sink. I also had to cope with "another woman" and to accept that also was due to his injury. I am a strong person.
Other	<ul style="list-style-type: none"> Previous experience Having an outside 'care-manager' to co-ordinate therapies, living skills, medical follow-ups, monitor 'scientific progress', move to new different levels of therapy etc. Time, love Avoiding dealing with it. Extremely supportive employer and spouse's colleagues

* Only 12 respondents answered this question.

Overall, subjects in the current study did not appear to rate *domestic help* as crucial. However, a limitation of the study is that type and frequency of domestic help was not probed - variables which may have influenced the results of the study. Information was also not sought regarding type of *medication* or whether medication was taken prior to the spouse/partner experiencing TBI.

Subjects reported that *friends* contributed most to coping with brain injury. Despite 5 subjects having reported that they had lost many friends since the injury, 10 subjects related stories of having been helped to cope with their crisis to a large extent by friends "who listened, cooked or spent time with my husband to allow me time out". Upon analysis of responses of subjects to a question assessing what had been *most* effective in helping them deal with the stresses resulting from traumatic brain injury, various common themes were evident, including *friends, family, religion, inner strength* and *medication*. Direct quotations reflecting subjects' coping strategies may be seen in Table 9.

Healthcare workers and counsellors should take cognizance of the positive coping strategies demonstrated by the spouses/partners of persons with TBI, in order to reinforce them and encourage their generalization to other difficult situations. It may also be helpful for rehabilitation personnel to attempt to discuss strategies to facilitate the coping of their clients such as recommending that they take vacations, keep a diary, attend inspirational lectures or use relaxation techniques. In addition, spouses/partners should be encouraged to participate in activities that have been found by others to decrease stress in an effort to enhance their perceived quality of life.

SUMMARY OF RESULTS

The findings in this study showed that a range of factors affected the perceived quality of life of a group of spouses/partners of persons who had sustained traumatic brain injury. Communicative changes were found to have detracted from the quality of life of most subjects in the current study, with the most frequently mentioned dysfunctional linguistic patterns being difficulty understanding hints; problems communicating in distracting environments; rambling, disorganized, tangential language; and word-finding difficulties.

Almost three-quarters of the current sample reported that their injured spouses/partners had not returned to work post-injury. The remaining quarter reported either part-time or alternative employment. Most subjects noted a drop in their income since the injury. Yet, no definitive trends were evident regarding satisfaction of subjects with their standard of living, implying varying perceptions of quality of life if satisfaction with living standards was to be used to gauge this phenomenon.

A change in family relationships, particularly the deterioration of the injured person's relationship with his/her children, was noted by all but one subject. Alteration of the relationship between subjects and the injured spouse/partner's family was prevalent, with reports of greater closeness being more common than increased friction. Reallocation of the injured person's

roles to spouse/partner was evident in the domains of financial decision-making, dealing with medical aids and social agencies, providing the main source of income, running the household and caring for children.

The vast majority of subjects in the current study reported that their marital relationships had changed since the injury, mainly owing to their spouses/partners' communicative changes, loss of sexual drive and personality changes, reflected particularly in their aggression and blunted emotion.

Emotional reactions of subjects to their spouses/partners' disabilities ranged from negative, for example, frustration, sadness, denial, burnout, to positive, for example, acceptance. Most subjects reported a perceived lack of independence and feeling 'tied down'. This finding was not surprising considering the frequent reports of complete or partial dependence of persons with TBI on their spouses/partners for transport, finances, decision-making and communication with unfamiliar people. The physical health of most subjects was reported to have suffered following the injury and almost all reported having been forced to postpone or cancel personal plans due to the injury. Loneliness predominated as a social consequence of a spouse/partner's injury despite the durability and support of pre-injury friendships. Finally, in terms of coping resources, psychological counselling was not reported to have been particularly effective, possibly because not many subjects had availed themselves of this service. However, supportive friends, family, religion, support groups and domestic help were believed by participants to be the most effective coping strategies.

CONCLUSIONS

Evaluation of the study was deemed necessary in order to assess its effectiveness and to gauge the value of its results. As such the limitations of the study were considered. Generalization of current results to the wider population of spouses/partners of persons with TBI in the country is limited due to the non-probability sampling, small sample size and disproportionate representation of the various ethnic, cultural and socio-economic groups in South Africa. In addition, gender effects could not be probed due to the disproportionate ratio of females to males. The small sample size also precluded the investigation of statistical correlations between variables. The questionnaire designed for data collection was quite long and detailed and required self-administration. This method of administration posed a limitation in terms of the reliability of the study since it allowed the possible misinterpretation of questions and furnishing of incomplete or sketchy responses. Ideally it should have been interviewer-administered to explain ambiguities and glean more detailed answers to open-ended questions. In addition, subjects may not necessarily have reported their beliefs accurately, being subject to social desirability bias or may have consulted other family members to assist them with the completion of the questionnaire.

Nevertheless, despite the limitations of the study, many important clinical implications emerged for speech language therapists, rehabilitation personnel,

spouses/partners of persons with TBI, families and friends of persons with TBI and these individuals themselves.

In this study, communication difficulties were found to contribute to subjects' perceptions of decreased quality of life either directly or indirectly through their effects on marital relationships, occupational and social opportunities. Speech-language therapists thus appear to have an important role in administering direct therapy to improve the communicative abilities of individuals with TBI. Following on from the findings in this study, direct intervention might include focusing on the development of the cognitive skills underlying language dysfunction, providing alternative methods of communication such as writing or gesture, encouraging word retrieval and conversational repair strategies including identifying and repairing breakdown, as well as developing increased linguistic and pragmatic skills. Findings indicated the need for direct speech-language therapy involving both spouses/partners and persons with TBI in order to establish more effective methods of communication in an effort to prevent conversational breakdown and preserve marital harmony. In addition, the study highlighted the role of the speech-language therapist in explaining the cognitive-linguistic origin of communication problems to spouses/partners in order to increase their understanding and tolerance and to decrease their frustration. Speech-language therapists appeared to have a crucial role to play in providing spouses/partners with emotional support as well as the information needed to explain the consequences of the injury to family and friends. It is acknowledged that counselling might be conducted by psychologists, social workers and other rehabilitation personnel who have contact with the brain injured population and their families, not just speech-language therapists. Moreover, counselling could be broadened to include not only individual therapy but also couple counselling, family-centred approaches, and group work which might possibly be more effective intervention modes. Thus, findings appeared to have implications for all potential counsellors regardless of their discipline.

Throughout the study, findings suggested the need for healthcare workers to be sensitive to the emotional, social, marital and financial consequences of the injury for the couple. Findings regarding financial difficulties pointed to the role of members of the rehabilitation team in helping spouses/partners to access financial resources by referring them to financial advisors or to the Department of Welfare for a grant or a disability pension. The injured persons might also be helped to find alternative occupations, possibly via referral to the Association for the Physically Disabled or the Department of Labour. At this juncture in South African history, the Employment Equity Act, legislates against discrimination in the employment of persons with disabilities. The necessity for counselling of spouses/partners to assist them to come to terms with the emotional and social implications of decreased financial status was also evident in this study.

This study appeared to have implications for the marital counselling of spouses/partners of persons with TBI, indicating the need for guidance regarding future expectations and long-term coping strategies to conserve marriages. Findings seemed to indicate that counselling of the entire family, particularly the children, should be

instituted to assist them to deal with the changes in family dynamics and with the altered communicative patterns of the injured person. Owing to the danger of role overload, findings pointed to the need to increase the capability of spouses/partners to deal with the burden of their new responsibilities. Rehabilitation personnel might thus assist spouses/partners to access resources that might lighten their burden, such as the hiring of a driver to assist with transport as well as equipping the injured person to resume certain roles and to undertake various jobs in the home.

The need for spouses/partners to seek or to be provided with increased opportunities for socialization was indicated, to overcome the loneliness and social difficulties that were evident in the study. In addition, rehabilitation personnel working with the target population need to be aware of the coping strategies that were found to have been successful in order to suggest them to other spouses/partners of head injured persons.

In conclusion, the current study investigated many of the aspects that were perceived to affect the quality of life of the spouses/partners of persons with TBI. Just as a seed rots in the ground before it germinates, destruction may serve to facilitate growth and development. As highlighted by LaPointe (1999, p.15), "Although quality of life may be altered, for every wreck there is a raft". By considering the various dimensions explored in the current study, rehabilitation personnel, family members and friends might contribute more significantly towards enhancing the quality of life of people whose spouses/partners have sustained traumatic brain injury, assisting them to make the most of their present situation and hence, to access their proverbial raft.

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APPENDIX A

INFORMATION SHEET

Dear Participant

I am a final year student of Speech and Hearing Therapy at the University of the Witwatersrand and am currently involved in research on the impact of traumatic brain injury (TBI) on the quality of life of the spouse/partner of the injured person. Research into this area has potential implications for improving our knowledge of the impact of brain injury on the quality of life of spouses/partners, the rehabilitation of persons with TBI, as well as counselling of their families.

I appreciate that you probably have a busy schedule, but would nevertheless appreciate it if you would complete the attached questionnaire and return it to me no later than _____, when I shall personally collect it. Please place the completed questionnaire in the attached return envelope and hand it in to _____ at Headway. The questionnaire may also be returned should you decide not to participate in the study. Please be aware that there are no right or wrong answers. All that is required is the answer that most accurately reflects your feelings and practices.

Responses will be kept strictly confidential and your anonymity will be preserved. In fact, you do not need to write your name anywhere on the questionnaire. Please note that your participation in this study is completely voluntary and that you may withdraw at any time without it being held against you in any way.

Should you wish to be given a summary of the results of the study, these will be made available on request. If you have any questions, I may be contacted at 646-2229.

Your participation is highly appreciated.

Yours sincerely

Fourth year student

Supervisor

QUESTIONNAIRE ON THE IMPACT OF TRAUMATIC BRAIN INJURY ON QUALITY OF LIFE OF THE INJURED PERSON'S SPOUSE/PARTNER

Demographic Information

Your Age: _____
 How long have you been married / living with your partner? _____
 Number of children: _____
 Age of spouse / partner: _____
 Time in years and months since the injury: _____

Communication

Which of the following describes you spouse/partner's language patterns both before and after the injury? (Tick whichever is applicable).

Before	After	
		Vague, sketchy, imprecise language
		Trouble understanding difficult spoken language
		Word-finding difficulty
		Rambling on and on, disorganized, going off on tangents
		Socially inappropriate language
		Very limited amount of speech
		Difficulty understanding complex written language
		Problems communicating in environments that are full of distractions
		Difficulty understanding hints (such as indirect requests)
		Problems understanding humour
		Trouble with abstract language (relating to concepts or events that are faraway in time or space)
		Difficulty following conversations

Please elaborate on the abovementioned / any other communication problems:

.....

1. Which of the following, if any, characterises your spouse/ partner's speech: (tick the relevant block)

Before	After	Not Applicable	
			laboured
			too soft
			stuttering
			too slow
			too fast

2. Do you find communication with your spouse/ partner tiring?

never	sometimes	often
-------	-----------	-------

3. Is your spouse/partner sensitive to the needs of the listener such that s/he:

yes	no	repeats, explains or rephrases information when s/he is not understood
yes	no	does not overestimate or underestimate the listener's knowledge of the subject being discussed

4. In order to convey what s/he intends to say, in addition to speech, does your spouse/partner use:

yes	no	writing
yes	no	gesture
yes	no	facial expression

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5. How often does communication break down between you and your spouse/partner?

never	sometimes	often
-------	-----------	-------

6. Does your spouse/partner often misinterpret what you have said to him or her?

yes	no
-----	----

7. Have your spouse/ partner's altered communication patterns had any effect on your relationship?

yes	no
-----	----

If yes, please elaborate:

.....

.....

.....

Occupation and Finance

1. Please fill in, marking with (F) to indicate full-time and (P) to indicate part-time.

Spouse/ partner's occupation before the injury: _____
 Has your spouse/ partner returned to work? _____
 Spouse/ partner's present occupation: _____

2. How does your present income compare to your income prior to the injury?

Income has:

dropped significantly	dropped slightly	stayed the same	increased
-----------------------	------------------	-----------------	-----------

3. How satisfied/dissatisfied are you with your present standard of living compared to your standard of living before the injury?

very satisfied	satisfied	neutral	dissatisfied	very dissatisfied
----------------	-----------	---------	--------------	-------------------

Family Life

1. Has there been a change in your family relationships since the injury?

yes	no
-----	----

Please elaborate:

.....

.....

.....

2. Do you feel that your relationship with your spouse/partner's family has changed since the injury?

yes	no
-----	----

If yes, please explain how it has changed:

.....

.....

.....

3. How does your spouse/partner's family react to him/her?

.....

.....

.....

4. Did the injury have the effect of bringing family members closer or estranging them?

bringing closer	made no difference	estranging members
-----------------	--------------------	--------------------

5. Does the extended family (i.e. aunts, uncles, cousins) visit as often as they did prior to the injury?

yes	no
-----	----

6. Does the immediate family visit as often as they did prior to the injury?

yes	no
-----	----

7. This question looks at your roles and responsibilities before and after the injury:

(Please mark your responsibilities with (My) and those of your spouse/partner with (His/Her).

	Before the injury	After the injury
caring for the children		
dealing with medical aid, social agencies		
making financial decisions		
running the household		
main source of income		

8. Please rate your spouse/partner's ability to perform the following on a scale of 1-5 (1 = very poor; 5 = very good):

	1	2	3	4	5
self-care e.g. dressing/feeding self					
hygiene					
household tasks					
shopping					
budgeting					
driving					

9. How do you feel about having to take over the responsibilities of your spouse/partner?

.....

.....

Marital Relationship

Please complete this section irrespective of whether you are married or living in a common law relationship with your partner. (Please tick the extent to which you agree/disagree with each item).

Statement	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. Our marital relationship has not changed despite the injury.					
2. My relationship with my spouse/partner has deteriorated as time has passed since the injury.					
3. We argue now more than we did before the injury.					
4. I accept my spouse/partner's limits.					
5. I have considered divorce.					
6. I feel as if I am married to a stranger since the injury.					
7. I have a close, confiding relationship with my spouse/partner.					
8. I keep my frustration inside myself.					
9. I am satisfied with my marriage.					
10. My spouse/partner can no longer fulfil my emotional needs adequately.					

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11. What changes in your spouse/partner (if any) since the injury, have most affected your marriage/relationship?

.....

.....

.....

Emotional Aspects

1. Do you live with the hope that your spouse/partner will wake up and return to his/her pre-injury self?

yes	no
-----	----

2. Generally speaking, how would you describe your personality before the injury? (Tick whichever is applicable).

anxious	
sociable	
independent	
easy-going	
other (please specify)	

3. How do you feel about your spouse/partner's disabilities? (Tick whichever is applicable).

angry	yes	no
accepting	yes	no
irritable	yes	no
burnt out	yes	no
sad	yes	no
frustrated	yes	no
other (please specify)		

4. To what extent is your spouse/partner dependent on you for the following? (Please tick the relevant item).

	totally dependent	somewhat dependent	completely independent
transport			
decision-making			
finances			
communication with unfamiliar people			

5. To what extent do you feel tied down and lacking in your own independence as a result of your spouse/partner's dependence?

to a great extent	somewhat	not at all
-------------------	----------	------------

6. Has your physical health suffered in any way as a result of the stress of your spouse/partner's brain injury?

Yes	no
-----	----

7. Have you had to postpone or cancel personal plans as a result of the injury?

Yes	No
-----	----

Social Aspects

1. Please tick the applicable answer:

I often feel lonely.	Yes	No
I feel responsible for meeting the social needs of my spouse/partner.	Yes	No
I feel that I have lost many friends since the injury.	Yes	No
I have made many new friends since the injury.	Yes	No
I avoid social contact.	Yes	No
I am embarrassed by my spouse/partner's behaviour in company.	Yes	No
My spouse/partner says the wrong things at the wrong time causing me discomfort in social situations.	Yes	No

2. How satisfied/dissatisfied are you with your present social life in comparison with your social life before the injury?

very satisfied	satisfied	neutral	dissatisfied	very dissatisfied
----------------	-----------	---------	--------------	-------------------

Coping Resources

1. Please mark the extent of the contribution of the following to your coping with the consequences of the injury? (Please tick those which are applicable).

	very helpful	somewhat helpful	not at all helpful
psychological counselling			
religion			
support groups			
domestic help			
friends			
medication			

2. What, if anything, has helped you most to deal with the stresses resulting from the traumatic brain injury?

.....

.....

.....

Thank you very much for your co-operation.

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INFORMATION FOR CONTRIBUTORS

1. Nature of publication

The *South African Journal of Communication Disorders* publishes reports and papers concerned with research, and critically evaluative theoretical and philosophical conceptual issues dealing with aspects of human communication and its disorders, service provision, training and policy.

The *South African Journal of Communication Disorders* will not accept material which has been published elsewhere or that is currently under review by other publications.

2. Manuscript style and requirements

- Articles must be accompanied by a covering letter providing the author's address, telephone and fax numbers and e-mail address.
- Articles must be typed on A4 pages in double spacing and in a font size of 12
- Three print outs of the article must be submitted.
- ONE exact copy of the article on disk must be submitted. Filenames must include the first author's initials and a clearly identifiable key word and must be type-written on the last line of the last page of the Reference list (for retrieval purposes only).
- Articles must not exceed 30 pages.
- The title page of ONE must contain:
 - Title of the article.
 - Full names of the authors.
 - Institutional affiliation.
 - Abstract of the article in the language of the article.
- The title page of the remaining TWO copies must NOT contain the author's names or institutional affiliations.
- Each article must contain an abstract of no more than 200 words.
- All abstracts must be in ENGLISH, irrespective of the language in which the article was written.
- Each article must provide 5-7 KEY WORDS for indexing purposes.
- All contributions are required to follow strictly the style specified in the Publication Manual of the American Psychological Association (APA Pub. Man., 1983).
- Headings are NOT NUMBERED. The order of importance is indicated as follows:
 - Main heading in capitals and bold print.
 - Sub-headings in capitals, bold and italic print.
 - Sub-subheadings in upper and lower case bold and italic print.
 - Sub-sub-sub-heading in upper and lower case bold print.
- Major headings, where applicable, must be in the order of **INTRODUCTION, METHOD, RESULTS, DISCUSSION, CONCLUSION, ACKNOWLEDGEMENTS, REFERENCES.**
- All paragraphs should be indented.
- All tables, figures and illustrations must be numbered and provided with titles.
- The title of tables, which appear above, and of figures, which appear below, must be concise but explanatory.
- Allow for 50-75% reduction in printing of tables, figures and illustrations.
- Each table, figure or illustration must appear on a SEPARATE page and be print ready. Preferable NOT printed on colour printers.
- Do not include more than 10 tables, figures or illustrations.

3. REFERENCES

- References must be cited in the text by surname of the author and the date, e.g. Van Riper (1971).
- Where there are more than two authors, after the first occurrence, et al. may be used from the start.
- The names of all authors must appear in the Reference List, which must be listed in strict alphabetical order in triple spacing at the end of the article.
- All references must be included in the List, including secondary sources, (APA Pub. Man. 1983, p. 13.)
- Only acceptable abbreviations of journals may be used, (see DSI-1 ABSTRACTS, October, or *The World List of Scientific Periodicals*).
- The number of references should not exceed much more than 30, unless specifically warranted.

EXAMPLES

Locke, J.L. (1983). Clinical Psychology: The explanation and treatment of speech sound disorders. *J. Speech hear Disord.*, 48 339-341

Penrod, J.P. (1985). Speech discrimination testing. In J. Katz (Ed.), *Handbook of clinical audiology* (3rd ed.). Baltimore: Williams & Wilkins.

Davis, G. & Wilcox, M.J. (1985). *Adult aphasia rehabilitation: Applied pragmatics*. San Diego, CA: College-Hill.

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DEADLINE FOR CONTRIBUTIONS: 30th June each year

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