NOTES FROM PRACTICE

UIT DIE PRAKTYK

THE TRAUMATIC ONSET OF DISABLING INJURY IN A MARRIAGE PARTNER: SELF-REPORTS OF THE EXPERIENCE BY ABLE-BODIED SPOUSES

ABSTRACT

This study explored the physical and emotional adjustment faced by female spouses of individuals who had suffered a traumatic brain injury (TBI, n=10) or a spinal cord injury (SCI, n=5). Results of this preliminary investigation show that the sequelae of brain damage and SCI necessitate major psychosocial change for the injured partner and spouse. Spouses of TBI victims cited their injured partner's change in personality as a serious problem, while partners of SCI sufferers identified depression in the injured spouse as a major difficulty. At the same time able-bodied spouses also reported attempts to cope with their own feelings of loneliness, depression, frustration and stress. In the current study, issues such as time since injury, length of marriage, or whether the injured spouse had returned to work were not seen as mitigating factors. Seventy percent of all the spouses expressed fears for what the future might hold. The study confirms previous findings that the stress of living with a TBI or SCI victim can increase over time. It is suggested that there is a strong need for ongoing community counselling services and support systems for these subgroups.

INTRODUCTION

When an individual suffers a disabling illness or injury, great demands can be placed on his or her family (Patterson 1988:209). Although the type of condition will influence the family response, intellectual and/or physical disability resulting from brain damage (such as stroke or traumatic brain injury (TBI)) or permanent immobility resulting from spinal cord injury (SCI), increase the burden of care (LeClere & Kowalewski 1994:459).

A life-altering illness or disability in children has been shown to have a negative effect on family function (LeClerc & Kowalewski 1994:458). However, when the victim is a spouse, especially in what has previously been a good marriage, the loss in emotional support can be considerable (Lezak 1988:122). Although the brunt of caring for and coping with the injured patient is borne by the able-bodied partner, there is very little information in the literature about disability and marriage (Parker 1993:566-567). Nevertheless, the altered situation can adversely affect the relationship and give rise to special problems (Parker 1993:566). For example, Parker (1993:578) perceives the difficulties that may arise as an alteration of the psychological balance of 'equity' within a marriage, which can be severely disturbed when one partner suffers physical or mental disability. Equity is conceptualised in terms of exchange and reciprocity, which are deeply embedded in close relationships such as marriage (1992.89). However, Parker (1992:90) believes that this factor is largely ignored by many workers in the field of disability and instead there is a tendency to paint an inaccurate "rosy picture of give and take". Thus individuals will maintain an invisible 'tally' of help given or received and strenuous attempts may be made to

redress perceived imbalances (Parker 1993:571). Parker (1992:90) also points out that while change may create imbalance, moves to redress the balance may be constrained by the lack of options available. In such situations "Notions of reciprocation sometimes come very close to notions of 'doing right' or of duty" (1993:574). In fact some studies have shown that where spouses remained married, they saw their roles as caretakers rather than marital partners (Maus-Clum & Ryan 1981:168). Follow-up studies of TBI patients over six years suggest a high incidence of marital breakdown (Maus-Clum & Ryan 1981:168). Similar results are mentioned by Rappaport (in Brook 1991:172), where just over a quarter of TBI patients in a study (27.3%) were living with parents 10 years after the injury, and 18% were living with spouses. With SCI victims the divorce rate quoted in the literature is regarded as disproportionately high (Crewe, Athelstan & Krumberger 1979:253). Although equity theory may be useful in exploring the able-bodied and disabled spouses' perceived inequities in the marriage and increase our understanding as to why able-bodied partners may remain in the relationship, it does not address the emotional issues that might arise within the dyad, especially those concerning the able-bodied spouse. Researchers such as Brooks (1991) and Lezak (1988) who work in the field of neuropsychology have noted that the changes resulting from traumatic brain injury specifically, can impact negatively on marriage and family life. For example, Rosenbaum and Najenson (1976:883) found that marriages in which one partner suffered TBI or SCI showed major changes. Some follow-up studies report loneliness and social isolation not only for the patient but especially for the able-bodied partner (Brooks 1991:179). It has been observed that because of emotional, behavioural and personality changes consequent to the injury, spouses of TBI victims had a more restricted social life and experienced greater isolation than those of SCI victims (Brooks 1991:164). Abrams (1981:257), however, cautions that mobility impairments, specifically in the case of SCI victims, are likely to affect marital companionship by decreasing the number of shared activities outside of the home. Overall, much of the literature has focused on the ways in which family members can adapt and assist the injured individual (e.g. Oddy & Humphrey 1980:800); few studies have addressed the needs of family members, especially those of the able-bodied spouse (Jackson & Haverkamp 1991:360). This study explores perceived changes in emotion and daily function reported by partners of TBI and SCI individuals. In addition, we investigated the adjustments and the emotional impact of such changes experienced by the able-bodied spouse. The aim was to identify the needs and available support for such subgroups.

METHODOLOGY

Subjects

The subjects were the spouses of victims who had suffered TBI and SCI. Permission was obtained from the relevant authorities in rehabilitation centres and hospitals in the Gauteng area to contact families. Out of the 26 TBI and SCI contacts seven TBI cases did not meet the criteria (couples married prior to the onset of disabling injury) and two refused participation in the study. Only five SCI contacts met the study criteria. The TBI group consisted of 10 female spouses, the SCI group of five female spouses. All the participants were mainly middle class, proficient in English and aged between 25 and 60 years. All of the participating TBI families had children, one of the participating SCI cases had no children.

Measurement

Questions were adapted from the Family Needs Questionnaire (Kreuzer & Wehman 1991) and from previous research surveys in this area (e.g. Rosenbaum & Najenson 1978). Information obtained included demographic information for spouse and injured partner (age, marital history, education), employment; perception of emotional and personality change in disabled spouse;

assistance required by partner (functional independence); satisfaction with lifestyle and perceived social isolation; pre-injury and current sexual history; self-perceptions of coping and stress in the able-bodied spouse.

Procedure

A pilot questionnaire was used to assess the clarity of questions, to check the time required to complete the questionnaire and to make amendments where necessary. Those who participated in the pilot study did not form part of the sample. The research procedure was then carried out. Each respondent was contacted telephonically by the first author. The purpose of the study was explained, consent was obtained and confidentially guaranteed. Each respondent was asked to complete the questionnaire as accurately as possible. Limitations of this exploratory study require mention. These include small sample size, limited generalisability and reliance on self-reports. The original aim of the study was to compare the SCI and TBI spouses; however, the small numbers involved do not permit valid comparisons. Data were analysed qualitatively, using percentages and frequencies.

RESULTS AND MAIN FINDINGS

Accident Type: Four of the SCI victims had been involved in motor vehicle accidents, one in a motor-bike accident. No SCI victim had a history of unconsciousness or concussion.

In the TBI group nine victims had been involved in motor vehicle accidents; all had suffered periods of unconsciousness. One participant had suffered a cerebral haemorrhage from an aneurysm, following which he had been comatose for 4 days.

Time since accident: A mean of 27 months since time of injury was found (range 11 months to 82 months).

Age: The ages of able-bodied spouses ranged from 25-60. The age range of the injured victims ranged from 28-60.

Education: Eighty percent of the TBI victims had 12 years of education and 20% had more than 12 years education. With the SCI group 40% of the victims had 12 years education, while 60% had more than 12 years. Eighty percent of the spouses in both groups had post-matriculation qualifications (e.g. typing/bookkeeping diplomas).

Employment: Fifty percent of the victims in the TBI group and 100% of the SCI group had not returned to work. Of the 50% in the TBI group who had returned to work, 30% were employed in a lower capacity than premorbidly. Sixty percent of the TBI spouses and 80% of the SCI spouses were currently employed.

Duration of marriage: Twenty percent of the TBI group had been married for 10 years or less, while 80% had been married for more than 10 years. In the SCI group 60% (3) had been married for 10 years or less while 40% (2) had been married for more than 10 years.

Professional Counselling: Four (40%) of the TBI and two (40%) SCI able-bodied spouses had sought psychological help following the injury. However, no able-bodied spouses were currently involved in ongoing counselling or therapy.

Perceived Personality and Emotional Changes

Ninety percent of spouses of TBI males were of the opinion that their partners had suffered some kind of personality change; 40% felt that memory was poor. In addition, 50% also reported observing increased irritability, impatience and frustration in their brain damaged partners.

Lezak (1988:114) reported similar findings of negative change following brain damage, the most difficult aspect being perceived characterlogical differences. Research findings also confirm that spouse caregivers are more likely to complain of changes associated with mood changes than parental caregivers (Hall, Karzmark, Stevens, Englander, O'Hare & Wright 1994:883). In the SCI group, depression was reported to be a common emotion experienced by the injured partners. Similar changes were also reported by McGowan and Roth (1987:362), who found that the SCI individual can experience severe emotional reactions such as anger, depression and frustration. (See Table 1.)

TABLE 1

PERSONALITY, MOOD AND MEMORY CHANGES IN VICTIMS OF TBI AND SCI INJURY AS PERCEIVED BY ABLE-BODIED SPOUSES

Description of change	TBI Group n=10	SCI Group n=5
Changes in personality	90%	0%
Problems with memory	40%	0%
Mood Changes		
Irritable/bad tempered	50%	20%
Depression	30%	60%

Spouses' Self-Reported Emotional Responses

In the current study it would also seem that able-bodied spouses were trying to cope and understand the changes in their partners, while simultaneously addressing their own feelings of frustration, worry, helplessness, impatience and depression (see Table 2). Respondents were asked to rate how strongly the perceived changes in their injured partner had negatively affected them. Of the TBI group, 50% reported being strongly affected, 40% moderately and 10% mildly. In the SCI group 60% reported being strongly affected, 20% moderately affected and 20% mildly affected.

TABLE 2

ABLE-BODIED SPOUSES' SELF-REPORTS OF EMOTIONS, FEELINGS AND STRESS IN THEIR CURRENT SITUATIONS

Description of change	TBI Group n=10	SCI Group n=5
Loneliness	20%	20%
Frustration	60%	40%
Hopelessness	40%	80%
Worry	40%	40%
Impatience	50%	60%
Depressed	40%	40%
Suffering severe stress levels	60%	60%
Suffering moderate stress levels	40%	20%

Stress and Coping

In response to the question "How much stress have you felt because of the changes in your spouse resulting from the injury/illness?" 60% of spouses of brain-damaged victims reported experiencing severe stress, while 40% of this group described their stress levels as moderate. Of the SCI group, 60% of the spouses reported suffering from severe stress, while 20% described their stress levels as moderate (see Table 2). Similar findings have been reported by Webb, Lorenzi, and Berzins (1982:108), and McKinlay, Brooks, Bond, Martinage and Marshall (1981:533). These researchers have suggested that the stress of living with an injured spouse does not resolve over time but may in fact actually worsen. In the current study it was found that the factor of the time since the illness or injury did not influence stress levels. It was also found that issues such as length of marriage, or whether the injured partner had returned to work could not be regarded as migitating factors in stress levels. This finding was unexpected in the brain damage group as 50% of patients had returned to work and had ostensibly recovered. This supported the findings of others (e.g. Lewington 1993:282) that more subtle aspects of disability can exist for the spouse, but can be less obvious to the casual observer.

Physical Problems and Daily Coping

With regard to physical changes and related difficulties, these were shown to be more problematic for SCI victims. SCI spouses reported that assistance was required with activities of daily living such as feeding (40%) and washing (40%). Although spouses of the TBI group reported that their partners did experience certain physical problems with dressing and washing, this was not as debilitating as the paralysis suffered by SCI victims (see Table 3).

TABLE 3

DESCRIPTIONS OF THE DAILY FUNCTIONING AND ACTIVITIES OF INJURED SPOUSES BY ABLE-BODIED PARTNERS

Activity	TBI Group	SCI Group
Feeds unaided	100%	60%
Dresses unaided	80%	20%
Washes unaided	80%	60%
Able to assist with chores in the home	40%	20%
Able to converse and interact with uninjured partner	70%	100%

Daily Interactions

Although spouses of SCI patients all reported no change in daily conversational abilities, 30% of the spouses of TBI individuals reported a reduction. A study by Burton and Volpe (1993:36) also noted decreases in communication between the TBI injured spouse and partner. This suggests possible cognitive changes or dysfunctional speech mechanisms or reflects reduced capacity to engage in social interaction. One TBI respondent in the current study noted that the exchanges were now more like those of a mother-child interaction. Researchers such as Brown and McCormick (1988:16) also point out the difficulties a spouse suffers adjusting to this altered situation.

Changes in Sexual Activity

Major changes were also reported in sexual activities. Seventy percent of spouses of brain-damaged partners rated their sexual relationship as 'unsatisfactory', whereas previously it had been rated 'good'. Sixty percent of the spouses of SCI victims also reported unsatisfactory sexual relations, which were good prior to the injury. The reasons for changes were not explored in the current study, although one TBI respondent stated that intimacy was difficult because of personality changes resulting in aggressiveness. Nevertheless, the responses are similar to the findings of Rosenbaum and Najenson (1976:887), who reported that both the spouses of brain-injured and spinal cord-injured victims reported a reduction in sexual activities leading to an unsatisfactory sexual life. These researchers found that reasons for these changes in sexual activity seem to be different for the two groups. In the spinal cord-injured group of subjects, the inability to function sexually is directly related to the spinal cord injury. In the head-injured group there was no clear-cut relationship between the locus of the injury and sexual functions (Rosenbaum & Najenson 1976:887). Lezak (1988:122) noted the impact of a situation in which the brain-damaged spouse has lost the capacity for intimacy and sensitive mutuality, so that sex changes from a sharing act to one in which the uninjured spouse is a passive tolerant partner.

Caretaker or Spouse?

Family roles are often apt to change because of emotional, physical and economic demands imposed by illness or injury (Carpenter 1974:272). These role changes require switches in well-

established habits that evolved through years of interaction and may lead to confusion and frustration. Evidence of role changes can be seen in the present study since 80% of the spouses of TBI partners regarded themselves as caretakers rather than wives, either sometimes or most of the time. Sixty percent of the spouses of SCI victims gave similar responses (see Table 4). Parker (1993:574) suggests that many carers adopt a caretaking role because they believe that they have a responsibility or duty to reciprocate for the role of 'good husband' or 'good wife' played by the injured partner in the past.

Thirty percent of the spouses of TBI victims found it difficult accepting the changes that had occurred in their lives as a result of the injury suffered by their partner, while 40% of the spouses of SCI victims experienced similar difficulties. As one able-bodied TBI spouse responded: "I can't get up and leave when I've had enough". Support from relatives was regarded positively by spouses in both groups, but was only reported in 40% of cases. However, it is important to note that 70% of all the spouses in both groups reported fears for what the future held for them. As an able-bodied SCI spouse noted: "What does my future hold? How long will he live? Who will look after him if I am not here?" Maus-Clum and Ryan (1981:168) found that wives frequently express concern for the welfare of their injured spouse in the event of their own serious illness or death. This is particularly true where there are no facilities for respite care. Asked whether they ever experienced any feelings of guilt, a total of 11 out of the 15 spouses (7 TBI and 4 SCI) responded positively (see Table 4).

Social Activities

According to Ray and West (1984:84), social activities are inevitably restricted as a consequence of disability and this was consistently communicated in the current data. Seventy percent of the spouses of the brain-damaged group reported deterioration in their social lives since the injury. Eighty percent of the spouses of the SCI group regarded their social life as more limited. (See Table 4.)

TABLE 4

ABLE-BODIED SPOUSES' SELF-REPORTS OF THEIR CURRENT LIFE-STYLE

Areas of perceived Change	TBI Group n=10	SCI Group n=5
Social life limited	80%	80%
Negative changes in lifestyle	50%	100%
Feels more isolated	10%	20%
Negative changes in marriage relationship	30%	40%
Sexual relationship unsatisfactory	70%	60%
Sees current role as caretaker rather than spouse	80%	60%
Difficulty in accepting changes brought about by partner's injury	30%	40%
Feels very uncomfortable leaving injured spouse alone	50%	40%
Fears for what the future holds	70%	60%

According to Brooks (1991:179), social isolation was a marked feature of follow-up studies conducted with brain-damaged and SCI families. Although in the current study the majority of respondents reported deterioration in social life, on the whole they did not perceive themselves as living in social isolation. Overall 10% of the spouses of brain-damage victims and 40% of the spouses of SCI victims regarded themselves as being socially isolated. However, this finding must be interpreted with caution in view of the small sample. When asked how comfortable they felt about leaving their injured partners alone, 50% of the TBI group reported feeling uneasy. Of the SCI group, 40% reported feeling some mild discomfort. (See Table 4.)

In the current study, 50% of spouses in the TBI group regarded their lifestyles as having changed for the worse, while all spouses of SCI victims regarded their lifestyle as having deteriorated; thus the implications of SCI seem to be more damaging than those of TBI (see Table 4). This could possibly be due to a number of factors, not least the nature of the physical caretaking role involved in SCI. Another factor is that despite higher educational levels than the TBI group, there was loss of employment for all the SCI cases, confining these victims to home environments. The other possibility suggested by Lezak (1988:123) is that TBI families and spouses take longer to accept the permanency of brain insult and continue to maintain hope that full recovery will eventually take place.

CONCLUSIONS

Although results of this study confirm and extend the findings of research that has been carried out in other countries, few studies in South Africa have looked at this area and its impact in other cultural settings. Further research in this area should be undertaken with a larger representative sample as it is essential to tap into the perceived needs of other communities. Since the literature also reveals that the burden on the caregiver does not improve, and may in fact deteriorate over time, intervention must not be limited to the confines of the rehabilitation setting; community support is vital. There is a need for effective follow-up services in the community that can respond to the needs of both the patient and the spouse. The availability of family therapy services such as support groups is necessary in assisting family members in reconciling the ongoing physical and psychological stresses involved with having a head-injured or spinal cord-injured spouse.

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