

Interaction with medical professionals following traumatic brain and spinal cord injury: relatives' reports



Curriculum Vitae

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Summary

Families have a strong need for support and the sharing of concerns especially during the acute period following a traumatic and disabling injury. In this regard families are persistent in seeking information about their loved one in the period following the traumatic event in order to understand and cope. This survey investigated family perceptions and interaction with medical personnel following a serious traumatic brain (TBI) or spinal cord injury (SCI) to a family member. Questionnaires were administered to the families of 20 TBI patients and six SCI victims. All the families interviewed were in the middle socio-economic range. Fifty percent of the respondents believed there was a delay in giving initial information about the patient's condition. The majority (85% TBI; 66% SCI) were given verbal explanations of the injury type, however, 60% of the TBI families complained of the use of technical terms. Fifty percent of the TBI and 33% of the SCI families felt that there were contradictions in the information given to relatives by different medical professionals. Despite the fact that 85% of the TBI relatives perceived the injury as serious, 75% anticipated a full recovery (ie that the patient would return to premorbid functioning and lifestyle). On the other hand only 16% of the SCI relatives believed that the patient would regain all functions. Overall, 60% of the TBI group and 83% of the SCI group perceived contact with the attending physicians as inadequate. Seventy percent of the TBI and 50% of the SCI group felt that social worker contact could be improved. Barriers to lucid and

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unambiguous communication are explored and ways in which relatives could receive clear explanations of the patient's condition together with realistic expectations of recovery are discussed.

Introduction

When a family experiences the stress of injury or illness to a member, the system moves into a crisis.¹ In such situations, families are vulnerable and look for help particularly from health-care providers who are seen as a source of assistance and information. Medical professionals can reduce ambiguity and help the family by giving information about the individual's condition, the treatment and the prognosis.¹ However, when a severe and handicapping injury occurs, such as a traumatic brain injury (TBI) or spinal cord injury (SCI), recurrent comments in the literature indicate that the family and their need for continuing information is often ignored.²⁻⁴

Cases of TBI and SCI in many ways epitomise the worst kinds of traumatic injury as they tend to occur in individuals who are young, active and healthy members of the community. When the injury occurs, the family enters a system of established medical services. This could be seen as a continuum of care which begins with the emergency situation and progresses according to the availability and knowledge of services and resources that the family may possess.⁵ Families are forced to work within this continuum, interacting with the medical professionals and this often gives rise to tension.⁶ However, the entire family is affected by a traumatic and disabling injury, and it is the patient's significant others, spouse, children and parents, who determine the kind of life that the person will have following such an event.³

Researchers² have commented on the importance of including families in planning acute and long term care of

all patients but especially the brain injured. This is because severe TBI causes irreversible damage to brain tissue and results in a constellation of immediate and long term mental dysfunctions. These dysfunctions are not well understood and perplex and frustrate the family.⁷ With SCI, damage to the central nervous system results in devastating immediate (and in the majority of cases permanent) disability, either paraplegia or quadriplegia. Here the family is faced with obvious changes in their loved one and their own life. While there is less ambiguity regarding SCI and the patient's behaviour, it has been noted⁸ that the lack of information about what is happening to the patient, especially in the acute care situation, makes it difficult for family members to deal with. It is not surprising that there has been an increased need for counselling both for survivors of serious TBI and SCI, and for their families in adapting to the changes and problems that follow such serious and handicapping injuries.⁹ However, in general, reports of the acute care and hospitalisation period show family perceptions of involvement and satisfaction are negative.¹⁰

Bond¹¹ points out that at the core of this issue there is among the medical professionals, an objective view of the TBI or SCI patient's physical condition. What is lacking on the part of health-care providers, is the need to understand the effects of changes in health and behaviour of the victims of such injuries on the structure and functions of the family. Theoretically this would involve a systemic perspective that would perceive the entire family as a client, broader than the medical model perspective where the emphasis is on disease and psychosocial issues are disregarded as in terms of the model they lie outside medicine's responsibility.¹² It is, therefore, not surprising that over the years families, particularly those of head injured victims, have complained about lack of consultation regarding the patient's condition and

The patient's kind of life after the injury depends on his immediate family.

Need to understand the effects of changes in health and behaviour of the victims.

Lack of information about what is happening to the victim makes it more difficult for the family to cope.

prognosis.^{13,14} Of course the other perspective is that the clinicians dealing with the patient usually do not know the family and may be inclined to say very little or to give the most pessimistic picture.⁴

However, if families are to make informed decisions about ongoing care and rehabilitation of their loved one, they must consult with the relevant medical professionals. Since the effects and perceptions of acute care may leave lasting negative impressions on the family, and engender bitterness and distrust for future contact with medical professionals, the following survey was undertaken with families of both TBI and SCI patients.

In this study relatives were asked to comment on the information they received about their loved one in the acute care and the post-acute period of hospitalisation, and their perceptions of contact with medical professionals during this time.

METHOD

The subjects

The subjects were relatives of patients who had suffered TBI and SCI and had been patients in hospitals in the Witwatersrand and Pretoria area. Permission was obtained from the relevant authorities to contact families. The TBI group consisted of 20 informants and the SCI group of six informants. Although both public and private hospitals were involved, and in some instances both, relatives' perceptions were based on the quality of the information received and the manner in which health professionals were perceived to interact with family members. All the informants were in the middle socio-economic range and aged between 25 and 60 years. Head injury relatives were nine mothers, nine spouses, one son and one father. The spinal cord group informants were two mothers and four spouses.

Instrument

Questions were adapted from the Family Needs Questionnaire by Kreutzer & Wehman,¹⁵ and from previous research surveys in this area.² The questionnaire was piloted on a small group which was not included in the current discussion.

Procedure.

Each family was contacted telephonically by the second author and requested to participate in the survey. The questionnaire was administered and completed in the respondent's home which also allowed for clarification of the questions. The original aim was to compare TBI families with SCI controls in order to identify issues related specifically to head injury as opposed to purely physical injury. However, this was not possible because of the differences in the numbers who responded to the request for information. All the TBI families contacted agreed to take part in the study, however, of the 20 SCI families contacted, only six responded and agreed to participate. Reluctance to take part in the study could stem from many reasons even an unwillingness to revive unpleasant memories, although it is not entirely clear why SCI families were less accessible than the TBI families.

The problems inherent in the study require mention: the group sampled represents only one community, the generalisation is therefore limited both to the area and population involved; the numbers are small and information is descriptive, presented qualitatively and is given in percentages.

RESULTS AND DISCUSSION

The patients

Twenty males had suffered severe TBI, five males and one female had suffered severe SCI. The average age for the TBI group was 33 years, ranging from 16 to

Perceive the entire family as a client.

Relatives' fears escalate if they do not get feedback from the medical staff.

Most families perceived an unnecessary delay in getting information from the medical personnel.

59 years (50% of the group was below 30 years). The average age in the SCI group was 45 years, the range 19-66. Length of time since the accident ranged from seven to 44 months.

In the TBI group, the injury was caused by automobile accidents (75%), falls (15%) and other (10%). All the SCI patients had been involved in motor vehicle accidents, no head injuries were sustained. With one exception, all the patients were living at home and had not returned to premorbid work or social life.

Background

In discussions on how medical staff interact with families, researchers such as Janet Williams⁵ describe situations experienced by the relatives following severe head injury to a family member. The main aim in these studies is to examine issues raised by relatives and to explore ways in which positive relationships could be created that would support families as well as medical professionals in their work together.⁵

A number of similar issues have been raised in the current study and include the following: perceptions of interaction in the initial crisis period; perceptions of how information was presented; perceptions of prognostic information; relatives' knowledge about the injury and the consequences; information given about rehabilitation; information given about resources for the family and the patient; relatives' appraisal of the support, social services and consultations.

Interaction in the initial crisis period

The initial interaction with medical professionals places family members in the role of passive recipients of information from the experts whose responsibility it is, in many instances, to save the family member's life. Talbott⁴ reports that a common early complaint is the lack of communication and the

difficulty in locating medical professionals to answer questions about the condition of their family member. Several reasons have been suggested, for example, there may be a failure by relatives to appreciate the emergency situation or it may simply be a form of denial.^{14, 16} Although it has been pointed out that physicians can only spare limited time for family members while the patient is in danger,¹⁷ it has been shown that relatives' fears escalate in the absence of feedback about the family member's condition.⁵ The perception of the time period that elapsed before the information was given, was explored in the current study.

In the majority of cases the time delay was in hours and in one case, several days elapsed before relatives were informed. Unavoidable delays, such as the outcome of surgical procedures, were mentioned. However, 50% (10) of the TBI and 50% (3) of the SCI respondents believed that there was delay in communicating with the family and more than half of these, or eight informants (two SCI and six TBI), perceived the delay as unnecessary.

A number of reasons were given including difficulty in finding medical professionals to obtain information, or delays in obtaining X-rays. These perceptions are important and concur with findings in other studies.¹³ The current survey shows that the need for information in the acute crisis stage is present and relatives do complain of feeling abandoned and neglected as other surveys¹⁸ have demonstrated.

The majority of relatives reported that the initial contact with a medical professional who informed them of the patient's condition was the doctor (TBI 40%; SCI 100%). In some instances a doctor and nurse were the informants (TBI 25%) or a nurse only (TBI 25%) or a nurse together with either a physiotherapist or a social worker were the first informants (TBI 10%). (See Table 1.)

Relatives feel left out, abandoned and neglected.

Families remembered how the information was provided longer than the content.

Table 1: Interaction in the acute and post-acute period

	Percentage responses	
	TBI	SCI
Perception of <i>delay</i> in giving information about the patient	10 (50%)	3 (50%)
Perception that <i>delay</i> was unnecessary	6 (30%)	2 (33%)
Initial informant/s		
Doctor/specialist	8 (40%)	6 (100%)
Doctor and nurse	5 (25%)	—
Nurse only	5 (25%)	—
Nurse and physiotherapist or nurse and social workers	2 (10%)	—
Verbal description of injury and condition	17 (85%)	4 (66%)
Verbal description plus scans and X-rays	3 (15%)	2 (33%)

Perception of how the information was presented

It has been established that families remember how information is provided by medical staff longer than the content.⁵ The initial delivery of the information can set the tone for future encounters with medical professionals.⁵ Mass-Clum & Ryan² believe that above all, the family require a clear and kind explanation of the patient's condition. Because the family is stressed, medical informants should be prepared to repeat information as often as necessary.² Much of what has been reported in other studies appeared in the current survey.

In response to a question regarding how they were assisted in understanding the patient's condition, 15% (3) TBI and 33% (2) SCI respondents said that they were shown X-rays and scans as well as given verbal descriptions of the injury, the majority (85% (17) TBI and 66% (4) SCI) stated that the information was given verbally. Relatives expressed appreciation seeing the X-rays and scans but stated that they had difficulties understanding them. (See Table 1.) This raises the issue of the use of technical jargon by doctors and specialists and in the current study 60%

(12) of the TBI respondents and 16% (1) of the SCI respondents felt that the information was too technical. Relatives do have difficulties in interpreting the information given. Williams⁵ points out that families are not familiar with the terms used, yet may hesitate to ask for clarification for fear of appearing incompetent. The problem here is as questions remain unanswered, the family may lose touch with what is happening to the patient. Although family education level could be an issue, it has also been suggested that because of stress and anxiety, families do not process information efficiently.¹⁷ This was observed in the current study in that requests for repetition of information were mentioned, in fact, one informant felt that what was needed was "to explain over and over again if necessary until the relatives understand the problem". The answer proposed by workers in the field is that information should, in the first place, be clear and without jargon, and in the second place, it should be repeated.^{2,5} (See Table 2.)

Prognostic information: giving a balance between hope and reality

It has been reported by several researchers that relatives vividly

Because the family is stressed, medical informants should be prepared to repeat information as often as necessary.

Information was too technical.

Interaction with medical professionals

remember negative predictions such as "He'll be a vegetable" and react to this information with shock and disbelief.^{2, 18} In the current study, perceptions of the information given varied. Fourteen relatives (12 HI, two SCI) were given negative prognosis, three (TBI) positives, three (TBI) uncertain, five (one TBI and four SCI) said the information was factual and in one TBI case the relative stated that information was withheld.

Fifty percent (TBI) felt that the information was insufficient and 50% (four SCI, nine TBI) felt they were given a complete picture of the patient's current status. Nevertheless, 81% stated that they would prefer to have a full picture including negative predictions of the patient's status at that point in time. However, according to the responses received from the 19% (four TBI, one SCI) who were given extremely bleak information, several perceived this negatively. According to one relative: "we were told that he would never wake up and that he would be a vegetable". This concurs with reports where families have strongly objected to early pessimistic predictions by medical professionals.²

Families often complain of gloomy predictions offered by clinicians but are in no position to challenge the information at the time.⁴ As one family member in the current study commented: "they (the doctors) only give you the worst position". On the other hand, it has been reported that surgeons and other medical professionals dealing with the patient at the time have their own anxieties about presenting what they see as an honest picture of the patient's condition and prognosis.⁴ It has, however, been shown that if negative informa-

tion is filled with inaccurate predictions, especially with head injury patients, (ie "he will never recover"), family members may begin to doubt the validity of any information offered by medical professionals,⁵ therefore, the perception of accuracy of the initial information is an important one.

Because the family see and recognise familiar behaviours and frequently

Families hesitate to ask for clarification for fear of appearing incompetent.

Table 2: Perceptions of information given

	Percentage responses	
	TBI	SCI
Information given about injury perceived as too technical	12 (60%)	1 (16%)
Information perceived as being insufficient	10 (50%)	1 (16%)
Information perceived as too negative	4 (20%)	1 (16%)
Information perceived as accurate	14 (70%)	5 (83%)
Information perceived as incorrect	5 (25%)	—
Unsure of information given	1 (5%)	—
Reported contradictions by members of medical team on information given to family	10 (50%)	2 (33%)

ignore the less desirable ones, they often perceive the prognostic information given to them as inaccurate. In the current study 70% of the TBI respondents felt that the information was accurate, 25% felt that they did not receive the correct information and 5%, or one respondent, was unsure. In the SCI group five out of the six respondents confirmed the accuracy of the information given. However, 50% of the TBI respondents and 34% of the SCI informants (46% in total) reported contradictions in the information and prognosis given by different professionals. For example, one respondent reported that the "nurses were always more positive about my husband's condition". Another commented on the incorrect but optimistic prognosis made by a physiotherapist and remarked that the doctor's prognosis, while gloomy, was at least honest.

Families do not understand information

Williams⁵ makes the point that not every professional will have the same degree of contact and knowledge of the patient's condition. (See Table 2.)

Throughout the stay in hospital, relatives require to be kept up to date about the patient's condition continuously and to be informed about changes or improvements. In the current study the kind of information conveyed about the patient's condition was explored and was as follows: descriptions of the injury and the damage sustained were given in 100% (TBI), 83% (SCI) of the cases and the medical procedures followed in 70% (TBI), 50% (SCI); 75% (TBI), 66% (SCI) of the informants felt that their questions were readily answered. (See Table 3.)

Knowledge about the injury and its consequences

Relatives have also raised the issue of their lack of knowledge of the problems that follow serious head injury while this was not an issue for SCI cases. With SCI the damage is, in the majority of individuals, physical and as Rosenbaum and Najenson¹⁹ found, intellectual and higher order mental functions are intact. With severe head injury, over and above the catastrophic accident, there is a unique and additional burden imposed by damage to

brain tissue⁹ but the effects of TBI on mental function as well as personality is difficult to explain to relatives.²⁰ In the current study, 50% of the relatives reported receiving information regarding the patient's difficulties in thinking and 30% were given information on the patient's behaviour. However, several respondents stated that they did not clearly understand at the time what the implications of the injury would be and no information was given to any of the respondents on how to cope with the patient's behaviours. (See Table 4.)

Several respondents commented that there was not enough information or preparation given for caring for the TBI or SCI victim. On the other hand, several informants stated that there was no need for such information, despite the fact that the injuries to the patient were extremely serious, which raises the possibility of denial. In this respect although 85% of the TBI relatives perceived the injury as serious, 75% anticipated a full recovery while only 16% (1) of the SCI respondents believed that

Table 3: Ongoing information to family

	Percentage responses	
	TBI	SCI
Ongoing information/description of injury	20 (100%)	5 (83%)
Medical procedures performed	14 (70%)	3 (50%)
Perception that questions by family members were answered by doctors	15 (75%)	4 (66%)
Perception that information was withheld	7 (35%)	1 (16%)
Perception of being kept well-informed	13 (65%)	5 (83%)

Be clear without jargon; and repeat!

Table 4: Information received about the injury and consequences

	Percentage responses	
	TBI	SCI
Information given about patient's thinking difficulties	10 (50%)	–
Information given on behavioural problems	6 (30%)	1 (16%)
Family perception of the injury as serious	17 (85%)	6 (100%)
Family anticipates full recovery	15 (75%)	1 (16%)

the patient would regain all functions. Preparing the family on caring for the patient following the effects of a serious head injury is difficult to explain to relatives, they must be specifically directed to known resources for consultation. Williams⁵ also raises the important issue as to where families can educate themselves about their own natural reactions to SCI but particularly TBI and its consequences.

Information about rehabilitation

The family role in the process of ongoing rehabilitation after hospital discharge is crucial. Williams⁵ perceives discharge from hospital and entry into a rehabilitation environment as a move away from the medical model to a systemic approach in which family involvement increases. Issues of rehabilitation, the benefits and prospects, are important to both family and victims, following TBI and specifically SCI. In response to the question on whether information given regarding rehabilitation was satisfactory, 66% of the relatives of SCI victims reported being given information on rehabilitation. (See Table 5.)

In the head injury cases 11 or 55% of the relatives were informed about rehabilitation. The nature of the information given was primarily concerned with physiotherapy and occupational therapy, in other words the physical aspects of recovery. No mention of the cognitive consequences or personality changes that can occur was made. It has been reported that many families of head injury victims do not realise the need for specialised rehabilitation following discharge from hospital beyond restoration of function.²¹ Williams points out that ideally, time must be spent with the family in explaining

the steps in the rehabilitation process. However, in the current study the overall impression was that family of TBI victims did not fully grasp the continuum of care which applies to head injured patients.

Information given about resources for both family and patient

The need for resource counselling, that is finance, legal, emotional counselling and support organisations, is essential for both the families and the victims of disabling injuries. Families do need assistance in coming to terms with the residual effects and the manner in which the family system must adapt. In the current study no information was given to SCI family members and one respondent commented that such information would still be welcome. In the TBI group, two respondents gave affirmation on this issue. One respondent obtained information on sources for emotional counselling for the family from a social worker while the other informant was directed to Headway via the patient's physiotherapist. This is a total of 10% which is less than the 20% reported in Mass-Clum and Ryan's study.² Although the information may be available, families depend on the professionals to bring such issues to their attention. (See Table 5.)

Appraisal for the support, social services and consultations

What were family perceptions of sup-

Physical rehabilitation is mentioned but never any mention of cognitive consequences or personality changes.

Table 5: Information to assist family

	Percentage responses	
	TBI	SCI
Information given about rehabilitation	11 (55%)	4 (66%)
Information given on resources:		
Finance	—	—
Legal	—	—
Counselling/help for the family	1 (5%)	—
Counselling/help for the patient	1 (5%)	—

port during the acute and post-acute period? Forty percent (eight) of the TBI respondents felt that there was no support, while the other 60% had much praise for what was done for them. Several commented on the excellence of the professionals, doctors, specialists, nurses, physiotherapists, occupational therapists and social workers, involved in supporting the family. A similar response rate was noted in the Mass-Clum and Ryan study.² However, these authors raise an important question which is who should give the family such support and information and who would the medical team designate? In the South African hospital situation the social worker services can play an important role in informing and preparing the family, however, only a minority of TBI informants, 30% (six) specifically perceived the social services in a positive light. For the SCI informants, 50% gave positive responses for the social services offered. Perception of staff empathy varied with 85% (17) of the TBI group giving responses ranging from excellent to absent. In the SCI group 83% of respondents' ratings ranged from good to lacking. Overall the responses of both TBI and SCI victims' families suggest a strong need for support and ongoing counselling. (See Table 6.)

In response to the question: "Did you have sufficient time with the doctors attending your relative?" 50% of the TBI group responded negatively. The most frequent comment was that "more contact with the doctors would have been appreciated". Positive comments were noted in that "the doctors' expertise was highly valued".

Conclusions

From the current survey of relatives of TBI and SCI patients the following observations were made:

- Any severe injury involving the brain or spinal cord requires medical model programmes and reliance by the family on medical professionals as experts. However, excluding the family from acute care information seems to generate resentment and anger. It is as Mass-Clum and Ryan² suggest that families want regular information, to be informed about the patient's condition and prognosis. In this way the family can begin to understand the injury severity and implications.
- Families seem to welcome information that is clear of technical jargon. The challenge to the medical professionals is the substitution of medical terms with everyday language.⁵

"The doctors only give you the worst situation."

Families need to grasp the continuum of care.

Table 6: Relatives' appraisal of staff interactions

	Percentage responses	
	TBI	SCI
Perceptions of staff empathy:		
Excellent	4 (20%)	
Good	5 (25%)	5 (83%)
Fair	8 (40%)	
Poor or lacking	3 (15%)	1 (16%)
Positive perceptions of family support	12 (60%)	3 (50%)
Positive perception of social services	6 (30%)	3 (50%)
Positive perception of nurses	17 (85%)	4 (66%)
Positive perception of doctors and specialists	13 (65%)	5 (83%)
Sufficient contact with doctors and specialists	8 (40%)	1 (16%)

- Relatives also appeared to resent information with strong negative predictions. This supports the view that clear, kind and factual explanations, free of inaccurate predictions, are preferable.² There is also the need to take into account that because of stress and anxiety, important information requires repetition.
- Relatives of disabled patients require help in finding resources where knowledge of the injury and its effects could be acquired as well as counselling and other help that may be needed. Williams⁵ also suggests that this would involve innovative strategies for educating the family (specifically in the case of TBI victims) about changes in the person and the family system. Family members may also require counselling for their emotional needs as well as legal and financial advice. The informants, specifically those of the TBI group, in some instances gave responses that strongly suggested a need for on-going help and support.

Family life is altered by the crisis of disabling injury and the families are in as much need of help as the person injured.² In a study of the relationships between health-care providers and families,²² three phases were observed from the family perspective. The first phase is naive trust during which the family assumes that its perspective is shared by the attending physicians. The second is disenchantment with the medical professionals reflected by dissatisfaction with care, frustration and anger. The third stage is one of guarded alliance which could be described as an uneasy collaboration incorporating both medical professionals and family perspectives. The current findings suggest that in the acute care situation the opportunity for establishing basic trust may be crucial. Failure to gain trust could result in perpetual 'disenchantment'. The population of the disabled and brain damage following traumatic

injuries grows and this situation seems unlikely to change in the foreseeable future so that extension of research into perceptions and needs of other communities in this area in South Africa seems warranted.

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