

The needs of family members of severe traumatic brain injured patients during critical and acute care: A qualitative study

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Abstract

Traumatic brain injury (TBI) is a devastating injury for both patients and their family members. The goal of this study is to identify the needs expressed by family members, as patients with severe brain injury progress through their recovery. A qualitative study was undertaken with 25 family members who

Les besoins des familles de patients avec un traumatisme crânien sévère en phase critique et aigue : une étude qualitative

Le traumatisme crânien est un évènement dévastateur pour les patients ainsi que pour les membres de leur famille. Le but de cette étude était d'identifier les besoins exprimés par les membres de la famille de patients présentant un traumatisme crânien sévère lors de leur hospitalisation. Une étude qualitative a été réalisée auprès de 25 membres de la famille de 15 personnes ayant subi un traumatisme crânien sévère. Les données ont été recueillies lors de 44 entrevues réalisées à deux occasions: lors du congé de l'unité de soins critiques (T1) puis lors du congé de l'établissement de soins aigus pour le retour au domicile ou vers un établissement de réadaptation (T2). Les résultats présentés font partie d'une étude mixte (qualitative et quantitative) plus large comportant trois temps de mesure.

Les membres de la famille ont identifié plusieurs besoins durant la période d'hospitalisation en soins aigus. L'analyse thématique à T1 a permis d'identifier quatre thèmes principaux décrivant la trajectoire de l'expérience des familles: Recevoir la nouvelle; l'incertitude; donner un sens à ces nouvelles; et aller au-delà. À T2, les thèmes ont inclus: l'incertitude; la recherche de progrès; la transition; et lâcher prise/reconstruire. Les besoins des familles identifiés ont été: gérer leur vie; être impliqués dans les soins; garder espoir; et recevoir de l'information, du soutien professionnel et du soutien dans la communauté. Les familles ont rapporté des besoins intenses lors de la phase aigue de l'évènement et que ces besoins ont changé avec le temps. Les résultats de cette étude aideront les infirmières en neuroscience à comprendre leur rôle au regard des besoins des familles lors de l'hospitalisation des patients avec un traumatisme crânien sévère.

were associated with 15 injured relatives. Data are reported from 44 interviews conducted at two time periods: discharge from ICU (Time 1) and discharge from acute care facility to home or rehabilitation (Time 2). The findings are part of a larger mixed method study of both qualitative and quantitative data collected over three time periods.

Family members identified a variety of needs during the acute hospitalization period. Thematic analysis at Time 1 identified four main themes that described the trajectory of the families' experiences: getting the news, uncertainty, making sense of the news and moving on. At Time 2, themes of the family experience included uncertainty, looking for progress, transition and letting go/building a new connection. Themes that identified the needs of families included managing life, involvement in care, and holding on to hope. Support required by the family included the need for information, professional support and community support. Families had intensive needs in the acute phase of the injury and their needs changed over time. Findings of the study will assist neuroscience nurses in understanding their role in providing for the needs of families of TBI patients.

Background

Traumatic brain injury (TBI) has long been recognized as a major public health concern, given the large number of patients affected each year and the morbidity associated with this condition. Conservative estimates suggest that 44 people a day sustain a TBI in Ontario, of which close to 7,600 individuals require hospital admission each year (Ontario Brain Injury Association, October 2005). While the sheer number of Canadians who sustain a severe TBI is impressive, it does not speak to the physical, psychological, cognitive and emotional impact of the injury.

The impetus for this study arose from the researchers' experience of seeing families struggle with the diagnosis of TBI. The challenges in the transfer of knowledge to families regarding TBI are numerous. Factors include limitations in the ability of CT to diagnose Diffuse Axonal Injury (DAI) and in the ability to perform a comprehensive neurologic exam when the patient is intubated. In addition, ICU staff may not be aware of the significant recovery that patients with severe brain injury may achieve. Also, the variability in recovery from TBI is significant. All of these elements contribute to the difficulty in providing understandable information to the family.

Literature review

Severe TBI is a devastating injury for patients and their families (Stebbins & Leung, 1998; Kolakowsky-Hayner et al., 2001), an injury that will forever change their lives. Significant variability in the physical, cognitive and social aspects of recovery exists, making the prognosis for the individual uncertain. Due to this uncertainty, families often exhibit intensive needs for information, emotional support and involvement in care, as they struggle to adapt to the changes in their life (Duff, 2002; Mathis, 1984).

Duff (2002) described how the family begins the process of “negotiating uncertainty” when their close relative has experienced a TBI. The family’s initial focus, during the critical period when the patient is in the Intensive Care Unit (ICU), is on the survival of their relative, followed by a focus on the hope that healing will be complete and the person will be restored to their previous level of function.

This need for hope was identified in several studies (Johnson, 1995; Engli & Kirsivali-Farmer, 1993; Mathis, 1984). While families want to receive realistic information regarding the patient’s prognosis, they also want medical professionals to give them hope for the future. Families in Duff’s study reported physicians, in particular, as being very pessimistic, resulting in the need for family to be physically near the patient during this uncertain time. In contrast, the families in Bond’s study (2003) wanted information that was realistic, regardless of the outcome.

The need for information during the acute care phase has been consistently identified as a primary need for families of severe TBI patients. In earlier research, Mathis (1984) identified the desire for medical information and the uncertainty of obtaining it as one of the central themes of families’ needs. Family members seek reassurance and support from the health care team during this period of intense uncertainty. Engli and Kirsivali-Farmer (1993) replicated Mathis’ study and confirmed that the need for information was a priority. Bond (2003) identified the needs of family members of patients admitted to a neurosurgical ICU. The need for consistent information was identified as problematic, with contradictory information being given by different staff. Five of seven relatives expressed the wish for uniform, condensed information by a single doctor.

Bond (2003) identified the family’s need to be involved in physical care and decision-making, which usually began three to six days after admission. Duff (2002) also identified the family’s desire to be involved in the care of their close relative, and reported that seeing the patient’s progress positively affected the family members. Family members eagerly watched for, and tried to provoke improvements in awareness and cognition. Positive responses by the injured individual reinforced and intensified family efforts. In contrast, the need to be involved in care was not reflected in the top 10 needs studied by either Mathis (1984) or Engli and Kirsivali-Farmer (1993). However this may be because these were quantitative studies, which did not present this option.

Duff (2002) and Grossman (1994) identified several aspects of recovery that are particularly stressful for families, such as transition from ICU to a hospital ward, or transition from hospital to a rehabilitation centre or to the community.

Purpose

The purpose of the study was to identify the needs of individual family members of a relative who sustained a severe TBI and to determine if these needs change over time.

Methods

Design

This study used a qualitative approach (Polit & Beck, 2010), using demographic information and semi-structured interviews over two time periods. The results are part of a larger study that employed mixed methods, using the Family Needs Questionnaire (FNQ), Frontal Systems Behavioral family rating form (FRSBE), State-Trait Anxiety (STAI) and the Functional Independent Measures (FIM) as quantitative tools, in addition to the qualitative data collection. Future analysis will compare additional qualitative data collected at six months post discharge from acute care, and triangulate it with quantitative data obtained from these same participants.

Study participants

Purposive sampling was utilized to identify family members of patients between 16 and 65 with a severe TBI, as defined by a Glasgow Coma Score (GCS) of nine or less within the first 24 hours and post-traumatic amnesia in excess of one week. A family member was defined as an individual looking after the physical, social, and financial needs and included parents, spouses and any other individual involved in caring for the affected person. Family members themselves identified who was considered family and was interested in participating. Most families identified two members to participate in the study. However, all research participants were interviewed individually. The study was conducted with English- and French-speaking participants.

Data collection

Data were collected over a 29-month timeframe and occurred in a Level 1 trauma academic health institution where care for patients and their families is provided from critical care through rehabilitation within one institution. Time 1 interviews occurred in acute care within four days of the patient having been transferred out of ICU. Interviews at the time of discharge from acute care (Time 2) occurred primarily in the same setting, or in rehabilitation or complex care settings, within one week of discharge.

Three open-ended questions were used to elicit the family member’s experience:

1. Can you tell us what it’s been like since (your family member) was injured?
2. What has been the most difficult for you since your family member was injured?
3. What has been the most helpful for you since your family member was injured?

Additional prompt questions were used to ensure specific areas were included in the responses (Appendix 1).

Qualitative data analysis

Thematic analysis (Braun & Clarke, 2006) was used to examine the qualitative data. The analysis of qualitative material begins with examining the data for recurring topics. Themes, which are abstract entities that bring meaning and identity to a current experience and its variant manifestations, emerge from the data (Polit & Beck, 2010). Qualitative coding methodology, as outlined by Streubert and Rinaldi Carpenter (2007), was used. Transcripts from the interviews were read and re-read in their entirety. A code book was developed so that phrases that described any aspects of the family member's responses were organized into codes based on similarity of responses. These codes were amalgamated into broader categories. Using an inductive approach (Fereday & Muir-Cochrane, 2006), categories were merged into themes. This process was undertaken over an 18-month period by the researchers and verified regularly through consensus decision-making with two researchers experienced in qualitative methods. A journal was utilized to record all data analysis decisions. The responses of individual family members at each of the time periods were compared both within and across Time 1 and Time 2.

Study results

Overview of study participants

Twenty-five family members participated in the study and 44 interviews were completed and analyzed. The majority of the participants in the study were female (84%) with almost half of them being mothers (40%) (See Table 1). Family members ranged in age from 16 to 58, with a mean age of 44 years.

Family members were associated with 15 patients who had sustained a severe TBI. Fourteen of the patients were male and ages ranged from 17 to 58 with the mean age of 30.7. All but three patients sustained their brain injury as a result of motor vehicle collisions, with two incurring falls and one construction incident (See Table 2, page 28).

Interviews at the time of discharge of the patient from ICU identified various preoccupations of family members. All descriptions were categorized and the transcripts generated 57 codes of rich descriptive data. Using a thematic analysis approach, 26 categories were extracted with the emergence of 11 resultant themes. Four themes described the trajectory of

the families' experiences: getting the news, uncertainty about the prognosis, making sense of the news and moving on. The needs of the family members identified the following themes: involvement in care, looking for progress, managing life and holding on to hope. How the family lived this experience was influenced by three additional themes related to support: information, professional support and community support (Figure 1).

These themes are described in the following transcripts. Note: "X" refers to the patient in the transcript.

Trajectory of the families' experiences at Time 1

Getting the news

Getting the news included the initial aspects of receiving the news, identifying the "inventory of injuries", and the "first look" at their injured relative. The family members demonstrated a need to recount in great detail the events surrounding the injury. The news that their relative was involved in a serious injury provoked an intense emotional reaction, which remained very vivid even at the time of interview.

I just grabbed all my clothes and got in the car and I was just like shaking... you automatically know when it is bad... I don't know how you know. (You have) the physical symptoms you just feel like... you can't even describe... it is awful (starting to cry). I don't know if you ever have that feeling again. You know, you just feel like you are going to vomit... you can't throw up... I never experienced that physical feeling that I had and it stays with you...

Uncertainty

After admission to hospital, "uncertainty" was a major sentiment that pervaded the family's thoughts. The initial focus of uncertainty was the patient's survival, which resulted in the family's need to be physically close to the patient. The theme of uncertainty comprised three phases: not knowing (whether the patient would survive, how severe the injury was), waiting (for information regarding their injury, for the patient to begin to wake up) and uncertainty (of their prognosis and how much the lives of the patient and family would change). Some families did not want to hear negative predictions and others felt a profound lack of control regarding the situation.

Relationship	Time 1	Time 2
Mother	9	5
Father	3	3
Wife	5	4
Sister	4	3
Girlfriend	3	3
Brother	1	1
Total	25	19

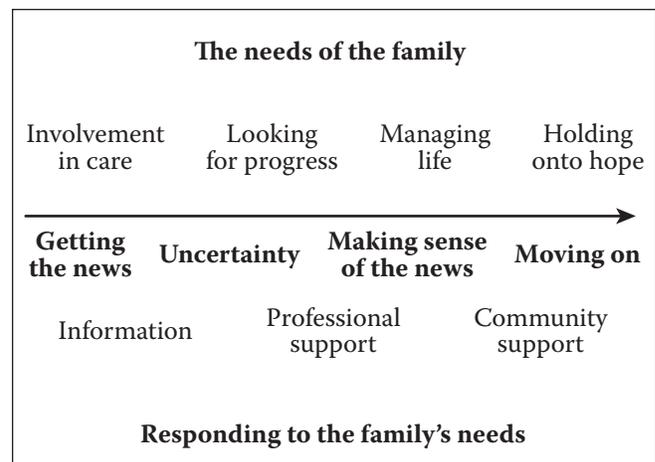


Figure 1. The needs of family members of severe TBI patients: Time 1 (11 themes)

Not knowing... ya, the difficult for sure is the not knowing. You know because you need a crystal ball and nobody knows and that would be the hardest, and especially in the ICU where we were waiting and not being able to help... and feeling so completely helpless and you can't do anything... you are just waiting. I mean he was so critical, like he was hour by hour you know, he was like that for days and that would be the hardest... the waiting and the unknown.

Making sense of the news

Making sense of the news comprised various themes, including receiving information about their relative's injury and progress; receiving professional support; looking for patient's progress and holding on to hope.

Moving on

Following the patient's transfer from ICU, families were already beginning to demonstrate the initial stages of "moving on". They had absorbed information about the injury and prognosis. They were beginning to shift some of their focus towards work and managing the family and were verbalizing initial thoughts about what adjustments might be required in the future.

The needs of the family

How the families lived the experience depended on two overriding influences: the families' strengths and inter-relationships and the support they received from professionals and

Table 2. Demographics of patients and family members' participation at Time 1 and Time 2

Patient				Family member				
	Sex	Injury	Age	Relationship	Age	Language	Time 1	Time 2
1	M	MVC *	38	Mother	65	English	√	√
2				Father	67		√	√
3	M	MVC	25	Mother	53	French	√	√
4	M	Construction	34	Wife	51	French	√	√
5				Father	59		√	√
6	M	MVC	17	Mother	42	English	√	√
7				Girlfriend	16		√	√
8	M	MVC	39	Wife	38	English	√	√
9	M	Fall	58	Wife	55	French	√	Nil
10	M	MVC	20	Mother/Sister **	46/21	English	√	√**
11				Girlfriend	19		√	√
12	F	MVC	19	Mother	48	English	√	√
13				Father	60		Nil	√
14	M	MVC	18	Mother	45	English	√	Nil
15				Sister	20		√	Nil
16	M	MVC	22	Mother	47	English	√	√
17	M	MVC	18	Mother	51	English	√	Nil
18				Sister	21		√	Nil
19	M	Fall	24	Mother	48	English	√	Nil
20				Girlfriend	28		√	√
21	M	MVC	48	Wife	48	English	√	√
22				Sister	44		√	√
23	M	MVC	51	Wife	50	English	√	√
24	M	MVC	37	Sister	37	English	Nil	√
25				Brother	44		Nil	√

* Motor vehicle collision (MVC)

** Study participant # 10 died between Time 1 and Time 2 and sister became the primary caregiver.

their community. The four family themes included managing life, involvement in care, looking for progress and holding on to hope.

Involvement in care

In the initial days and weeks immediately following injury, the family focused almost exclusively on the injured person and maintained a constant presence by the patient's bedside. The need to be close was the primary way families were involved during the initial stages. While some families felt detached due to the severity of their relative's injuries, simply being present made others feel involved.

My needs didn't matter; nobody was going to kick me out of there. It was my baby—it was my blood, and even though there were nurses, I just would not leave my baby.

Supportive hands-on actions such as putting cream on the feet and wiping the mouth were specific activities that gave families a sense of involvement and feeling close to their relative.

Looking for progress

Family members spent extended periods of time with the patient, and were extremely vigilant about noticing and reporting small improvements in the patient's behaviour. These behaviours provided a basis for optimism that the patient was improving and hope that the progress would continue. As patients became more interactive, families were able to distinguish the moment where they began "connecting" to their environment. The first time they opened their eyes, the first time they responded to commands, the first word they spoke—all were intensely positive moments for the family.

And I remember it took almost two weeks till she started opening her eyes just a little bit. And after that it went fast, within two or three days I think, she had her eyes wide open. She wouldn't move them too much and had a fixed look but, then again, within a few days she started following us in the room. Then it got better, got better because we knew she was saved—she wasn't dying.

Managing life

During the initial period following injury, the family focused on the injured person, while other responsibilities were postponed or delegated. As it became evident the patient would survive, but that recovery would be prolonged, family members began to recognize that other family obligations, work and community life must take precedence.

I leave at night and then I go home and I kind of pamper (my son) because I don't want him to think that he is not important. For me, it's important that he knows that today I was with the daughter and tonight I'm here and I'm cooking for you.

Holding on to hope

The family's perspective, determined by their emotional response, their positive outlook, their past experience, hope and spirituality impacted how they gave meaning to the situation. While some family members described emotional responses of sadness or detachment, others shared feelings of being positive, optimistic and hopeful.

I cried for, it must have been eight days, non-stop. The team used to come around and do their rounds in the morning and

I'd just be sitting in the chair with my great big tissues and I'd just be listening to them and the tears would be pouring down my face and they kept looking at me. So it's been hard.

Another family said: "I really felt that... from the beginning, that it was going to be OK. Just the bottom of my gut, but I don't know if everyone thinks that about their family."

Responding to the family's needs

Family members needed significant support from professionals regarding information and emotional support, as well as emotional and instrumental support from family and friends.

Information

The need for information generated the greatest number of descriptors from the family. The family expressed an intense "need to know" about their relative's injuries and what the prognosis was. Most families wanted information that was consistent, understandable, honest and updated on a frequent basis. The families needed information that was specific to their relative and not based on statistics or probabilities. While most families felt well-informed, some members were not reassured and felt they needed more information.

Professional support

This theme consisted of the manner in which families felt supported by the health care team. All references to interactions between the family and the professional staff, except those related to information, were coded in this category. Families were overwhelmingly positive about their interactions with staff, in particular nurses (especially in ICU), physicians and social workers. The combination of relevant, understandable information being delivered to the family in a way that was consistent and caring established the development of trust in the family. This sense of trust was reinforced by all positive interactions and diminished by negative ones. Concrete supportive actions identified by the family included access to the patient, a comfortable environment and responsive staff. Staff members who demonstrated confidence, were upfront and honest, and who responded to family requests, provided reassurance to the family. Early identification of needs and respecting the individual were also key concepts expressed.

The residents were great... the doctors were really good... again good explanations of things. Lengthy, you know... not just brushing you off, they go into depth. You know, they were kind and had a nice bedside manner.

While the vast majority of responses regarding professional interactions were positive, some concerns regarding care were identified. Interactions that the family felt negatively about focused on staff who did not know the patient and who made them feel insecure about the care that was being given. As one family member verbalized, "We have had a few instances where we were very unsure about the nurses and knowing his history and that was very unsettling."

Community support

Social support theory (Stewart, 2000) defines three aspects of functional support: emotional, instrumental and informational support. Emotional support from family and friends during the time the patient was in ICU included visitations, receiving

phone calls, receiving cards with messages of prayers and hope, and having family ask the “right” questions of hospital staff, especially if they had a medical background.

We ate... we cried a lot... we came to the hospital. And it was loose... it was supportive. I can't say enough about those two men and their genuine concern for me... that brotherhood that men have... that they are going to look after their brother and cousin and that his family is included in such a generous warm way (crying).

Families sometimes found the magnitude of phone calls from friends and relatives overwhelming. All of their energy was focused on their relative and dealing with other people's questions left them drained. The hospital staff was often able to assist families by limiting the number of calls at the hospital and by supporting their decision to limit their interactions with extended family and friends.

Instrumental support from the community included the delivery of meals, transporting family to hospital and children to their activities, mowing the grass and providing money. It also was evident in terms of family member's work environments being emotionally and financially supportive.

Results at Time 2

Trajectory of the families' experiences at Time 2

Time 2 reflected the period between the patient's transfer from ICU and discharge from acute care. The amount of time varied depending on the patient's recovery and ranged from 17 days to 134 days. Although all patients were initially diagnosed with a severe brain injury, they experienced vastly different degrees of recovery. Some improved significantly and were being admitted to a rehabilitation program, while others remained in a semi-responsive state and were transferred to complex continuing care.

The researchers extracted 27 categories with the emergence of 10 themes. Many of the same needs identified at Time 1 remained important, but the significance and the nuances were altered. Families evolved along a trajectory from uncertainty to looking for progress, to transition and finally letting go/building a new connection (Figure 2).

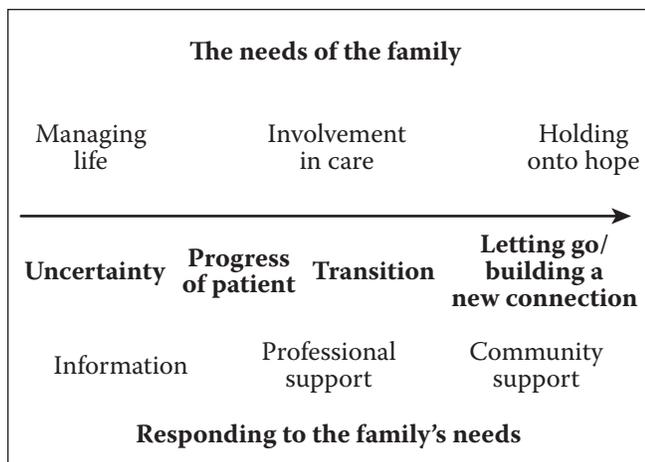


Figure 2. The needs of family members of severe TBI patients: Time 2 (10 themes)

Uncertainty

Although uncertainty continued to be a preoccupation of family members, especially when the patient had shown limited progress, it now focused on what quality of life patients would have, rather than survival.

The most difficult, I guess, would still be the “not knowing” part, not knowing the extent of his injuries, not knowing what damage has been done, not knowing if he is going to know us, to be able to speak to us, to be able to walk, talk, or whatever. Umm, that's the most concerning right now. And, we don't know what to do—will he be in a long-term care facility and dependent on others for the rest of his life? That's not a very happy thought right now. That's the most difficult thing... just not knowing.

Looking for progress

The patient's actions and behaviours had a significant influence on the family's feelings about their recovery. As the patients progressed, the variability of patients' actions from day to day encouraged the families when it was positive, but was very disheartening when the behaviours showed regression. Families continued to search for indications of “returning to normal” and to monitor the patient's behaviour very closely in order to identify any positive changes.

She was pulling at her tubes and I told her, “No, take my facecloth” and I put it in her hand and she said, “No”—that's the very first word she said—and she threw the facecloth. She was mad. But she knew I was there because she looked at me and it was not an empty look—it was very lively.

Transition

The transition from one level of care to another was often a difficult time for families. The difficulty that the families experienced was due to many factors, including the need to adapt to different staff, the change in pace of the unit, and the perceived delay in care while the patient was being assessed. Many families had spent weeks on a particular unit, at a very difficult and stressful period in their lives. The support and familiarity they had come to know was suddenly changing and it was hard for the family to adapt to the new environment. Many of the less-positive comments regarding professional support occurred during the transition from acute care to rehabilitation or complex continuing care.

(When you are) going in to an acute care setting every day and you get to know people and there was a routine that went with that and you can almost mask the actual injury... So ya, it was really difficult and now I have been here (complex care facility) for a week—it's like you have to start over again; you have to establish relationships with new nurses and home care providers and doctors and a... a frustrating aspect to that is you see someone one day and then you may not see them another day and it is a whole process that starts all over again. It can be... ya, daunting... and wearing.

Transition was especially difficult for families if the patient's recovery was limited. Having a relative transferred to a complex continuing care facility was seen as a negative sign, and re-emphasized the severity of the injury and the poor prognosis for the future.

It didn't matter if it was the Taj Mahal, I still didn't want to be there, I didn't want my husband there emotionally, and it sort of hit me—the reality of his head injury. Our three children also articulated it very similar to that—they had to go into this facility and see their dad there and they knew that his injury—was a serious injury.

Letting go of the past/Building a new connection

Families whose relative remained severely compromised began to accept that the injury had forever changed the person they once knew. Severely injured patients were not capable of caring for themselves, which affected family's interactions at both a cognitive and a basic care level.

Certainly the brother I knew doesn't exist anymore.... Because once your brain changes, it is not the same. He is not dead, but the brother I talked to... doesn't exist anymore. And whenever my brother comes out of it (coma), I will be meeting my brother all over again—someone different. So you have to accept that... which I have, but at the same time I wish I had stopped and talked to him longer... I should have taken another half hour, but I said "I will talk to you tomorrow." Well, tomorrow never came.

Needs of the family

Three of the family themes identified at Time 1 remained relevant at Time 2: managing life, involvement in care and holding on to hope. Because looking for progress became such an integral component of the family's experience, it was categorized as part of the trajectory of dealing with a relative with a severe TBI.

Managing life

Following the critical period, managing life became one of the most demanding aspects of dealing with a relative who was brain injured. Five sub-themes were identified: managing the family's routine, managing interpersonal conflict, managing the patient's care, managing practical issues and managing self care. Managing the family's routine, the patient's care and practical issues focused on the tasks of being at the hospital with the patient, providing food for the family, washing laundry, dealing with school, dealing with insurance companies, organizing appointments and transportation. Tasks were often given to different members of the family to avoid conflict and to divide the required work so that one person didn't bear the brunt of the care.

Managing interpersonal issues

Managing family relationships became intensified due to the stress of the situation and the uncertainty they faced. In families where interpersonal conflict was already present, the stress of having someone with a brain injury intensified the situation and sometimes resulted in a deterioration of relationships.

...the other thing that's arisen is the dynamics (within our family). It's been very difficult. It's been a hardship, like a fall full of hardships with, you know, just our relationship really. You know, it's been difficult because I think she's probably had a very severe reaction to this. Obviously her husband has a severe head injury and it's been hard for me to watch her go through that—the different stages that she's gone through and sort of knowing how to best deal with her in terms of my relationship and how I could best help my brother through her...

Conflict between parents and girlfriends arose and created more difficulty in dealing with an already challenging situation.

Managing self-care

Self-care aspects included activities that family members engaged in to ensure they had enough time for sleep, nutrition, work obligations and leisure. For most family members, the focus of their energy remained with the patient's needs, although the shift towards recognizing their own needs was beginning to develop.

My own needs? To myself, the way I felt was that I put everything for myself on the back burner. I felt that that was not important because the only thing I had on my mind was my husband and that I wanted him to get better to come home to us. Now I know that that was not the best decision not to take care of me, but I wanted to be there for him.

As the length of time in acute care became extended, families began to realize that recovery would be prolonged and they had to begin making time for their needs.

I would spend the whole day there doing the same thing, but after a couple more weeks, I don't know, I realized I couldn't take it anymore. So we made an arrangement. I would go in early in the morning, (and then) go back when my ex would go home and stay with her 'til she fell asleep. That was hard.

Involvement in care

Families defined involvement in care in the manner that was most meaningful to them. Some family members were extremely involved in all aspects of the patient's care; others saw their role as helping the staff to understand their relative. Parents of young adults or wives were most involved in giving physical care. For wives, in particular, being involved in this way made them feel that they were helping their husband. All families were very committed to being there for the patient, to understanding what their plan of care was and to ask questions. Being a patient advocate, commitment to the patient and planning for the future were identified as sub-themes. Some family members wanted to be more involved, but were uncomfortable about caring for a person with such significant injuries, and were concerned that they "do the right thing". Nurses played an instrumental role in helping the family become more involved.

Well, I was very nervous at the beginning, but they make it very, very gradual and I remember we started that—with the nurses. One of them asked (me if I wanted to help wash her hair), and I was pleased to do it, but I was very, very nervous. But I was offered an opportunity that I could have not taken, but I did and was happy I did. I really felt they let us play the role when it was time for us to. They made us a place and I felt better 'cause I could feel X felt secure.

Holding on to hope

The descriptors ranged from having a positive outlook, recognizing the value of maintaining hope and being supported by spiritual aspects, to feeling guilty about enjoying life and being overwhelmed and very fragile and losing hope that things were going to change significantly.

Yes, I always kept a positive side. I always looked at the positive side. Even though sometimes I felt that I was not strong enough, but I always repeat to myself, "I have to be strong for him. He needs me". I've had my days. I cried a lot. I was not well with myself. But I prayed a lot and I kept that positivity. And I never let anyone say anything negative.

Families relied on professional staff to encourage them to maintain hope and paid close attention to words of encouragement. Physicians were seen as being more pessimistic so encouraging words from them were particularly poignant.

Those people who say "Don't give up", "Remember we've all seen miracles", they're not trying to confuse the issue or anything like that; I don't think they're offering false hope. They're just saying, you know, "Keep the faith" type of thing. And that, I think, is a positive thing that is coming out... Some of the doctors aren't quite as optimistic; they're a little bit more pragmatic and practical. "Well, this is what happens in this instance and this is what happens in that instance." Umm, but it was a doctor who said, "We've seen miracles happen"

Families spoke with others who had had similar experiences and "surfing the net" for stories of miraculous recoveries. They wanted time for their relative to recover, and didn't want their hope to be destroyed, although they realized the severity of the injury.

You understand the injury, but you are not prepared to say there is no hope and say goodbye, like four months... that is premature... let's give him some space—time.

The emotional turmoil members experienced remained significant during acute care, in particular when the patient's progress had been limited and their status remained significantly compromised. The fragility of the family member's emotions was evident and simply talking about their experience brought tears to the surface.

Family members experienced feelings of guilt when they felt they were enjoying life while their relative was confined to a hospital bed because of their impairment.

This is the worst... there is an element of my husband... you know he knows that he is not in a good space right now and it is certainly heartbreaking... heartbreaking. This is where a shadow of guilt comes through. They told me that I would have to deal with guilt and I didn't get that when they said that. "I didn't do anything wrong." But my kids wanted me to decorate the house for Christmas and I... didn't want to do that. But you decorate your house for Christmas and you look around and it looks so pretty and you... like, oh my God... my husband is in a hospital room and I'm in this beautiful home and all nicely decorated.

Responding to the family's needs

The patient's progress and the information and emotional support that they received from professionals helped them to understand and accept their new reality. The support of members of their community became more important, as families continued to strive to manage the demands of everyday life while maintaining their involvement in their relative's care.

Information

In the acute care stage, communication of tangible information regarding the severity of the injury, the steps of the recovery process, and plans for transfer to a different level of care became pertinent. Although the need for information remained important, the intense "need to know" diminished. The number of exemplars related to information needs decreased by more than 50% from ICU to acute care. Most families realized that there were no definite answers and that they were able to judge the patient's progress in much the same way the professionals were able to.

Nobody could tell us the time thing and we understand that... you just always want to know, but there is no real answer. It is sort of unpredictable, so they told us what they could... give us the negatives and the positives—which we always didn't want to hear the negatives, but they have to and that is the way it is. The positives come along. You just feel you have another accomplishment and they are there to support you.

Professional support

This theme, where families described feeling supported by the health care team, elicited the most descriptors during acute care, which may suggest that emotional support from professionals becomes more important than the need for information at this stage. The majority of the descriptors referred to the positive support provided by the team as a whole, rather than to particular individuals. Nurses were identified as providing support most often, with about half of the exemplars describing nurses specifically. One reason nurses were so appreciated was because they spent so many intimate hours with both the patient and family, and developed an extremely close link, leading to expressions of being treated as family. Competence and effective communication were two key factors contributing to positive descriptors of nursing care.

The nurses make you feel at ease by two ways: you get a good sense of how competent they are... the level of competency, their level of enthusiasm and attentiveness that puts you at ease... that's support. You know when he is being taken care of by a conscientious dedicated individual, and you know right off the bat who that is, and who it isn't. That's... that's half the stress released. And then the way they communicate with you. Those are all huge (emphasis) things that reduce the stress and involve you in the care of the person.

Physician support was often linked to brief communication that was delivered in a supportive manner.

Community support

Community support continued to be a vital factor that assisted family members in coping during this challenging period. Emotional support from family and friends was described as a necessary part of the recovery, so that families didn't feel alone in dealing with the challenges.

Oh, the most helpful has been the support that we're getting from his friends and our friends and our families. It's very important to have that support because you're not in this alone, this continues to be a major part of our rehab, both my wife and mine, 'cause it's a long process and we need some support from friends and families and we're getting it, and it's helpful.

When patients remained severely injured and were non-responsive to visitors, family members were concerned that the emotional support, especially from the friends of the patient, would begin to lessen as time went on and no improvement was evident.

As the time has gone by, I think that perhaps, I shouldn't say that their interest is less, but I've indicated to them by emails and things that umm, "even a kind word or a hug or whatever, is so uplifting," and umm, "please don't stop" is what I've said. So I'm getting little tiny email messages back saying "baby steps" and "keep it up" and "we're thinking of you"... We need this support and we need it to continue.

Instrumental support, as reflected by the assistance of insurance and financial services and work accommodation, began to be a priority, as transfer of the patient to the community became imminent. Insurance assistance, which most families had access to, as the majority of severe injuries were the result of motor vehicle crashes, was important in helping families.

But the fact that the insurance company has been there and is there to provide the financial support, otherwise, we just couldn't cope. But that need has been very realistic. Now we realize how important it is because otherwise, financially speaking, it would have been just overwhelming, we don't know how we'd handle it.

Discussion and comparison of critical and acute care needs

Significant differences in the family members' experiences emerged on transfer from ICU (Time 1), as compared to the time of discharge from acute care (Time 2). Initial priorities included the need to recount the circumstances of the injury in detail, tremendous uncertainty regarding the survival and prognosis for their injured relative, making sense of the information they were receiving and beginning to move on towards acceptance of the consequences of the injury. In contrast, at Time 2, that intense uncertainty had diminished, in particular when the patient had made noticeable progress, and the family acknowledged that a new relationship had evolved and they were beginning to move on to a new reality. Although their experience differed during the two time periods, the resources that families used to help them cope remained similar, although the nuances and details of these themes differed. Information and support from health professionals, as well as from the community, remained important as families became increasingly involved in the patient's care. The challenge of managing the family became more of a reality and although the need to maintain hope remained strong, the strain of dealing with this injury began to be evident.

The initial uncertainty and need for information is reflected in previous research by Duff (2002), Bond et al. (2003), and Engli and Kirsivali (1993). Bond also identified the need to make sense of the experience as a high-priority need. At Time 2, the need for information had evolved from the intense "need to know" to a need for consistent information

on the longer-term prognosis. Families were becoming adept at evaluating the patient's progress themselves and realized that there were no definite answers in terms of the speed or degree of recovery.

Professional support superseded the need for information, as families began to understand the severity of the injury and needed support in their adaptation. Unlike Duff (2006), this study found that family members were very satisfied with the care given, particularly in the ICU, but also at the intermediate level of care. Duff suggests that the lack of continuity of patient assignment was a major factor in the family's dissatisfaction, whereas continuity of nursing assignment and specialty knowledge of traumatic injury were present in the study environment, which may explain the differences in results.

The need to be involved, also identified by Bond and Duff, was significantly transformed between Time 1 and Time 2. Although most families felt involved throughout the experience, their initial involvement centred on being present and providing a supportive role. Over time, most families began to assume the physical care of their close relative, and family members verbalized the need for support and encouragement from staff to allow them to gradually increase their comfort.

Following the injury, all energy focused around the injured relative and "managing the family" was achieved primarily by letting others do necessary tasks while they remained at their relative's bedside. Protecting other family members from stress was a priority and self-care was nominal. In contrast, at discharge from acute care, although the focus remained with the injured relative, families had organized themselves and were beginning to divide responsibilities. They realized that they needed to care for themselves in order to have the stamina that would be required over a prolonged period. These findings have not been previously identified in the literature.

The extent of the patient's progress significantly influenced the family's response and needs through critical and acute care. Similar to Duff's study, family members eagerly watched for improvements in the patient's response. Families of patients who remained impaired expressed more uncertainty and emotional difficulties, and required more professional support. Duff suggested that these families had difficulty maintaining a positive outlook, which was not seen in this study. Similar to Johnson (1995) and Engli and Kirsivali-Farmer (1993), these family members emphasized the need to maintain hope, although they expressed feelings of guilt at enjoying life while the relative was hospitalized and had difficulty with the transition to a long-term facility.

The need for ongoing community support was evident throughout the families' experiences. However, it transformed into a new reality upon the patient's discharge from acute care. Emotional support predominated initially, but the need for instrumental support gained importance as the injured relative returned to the community. Insurance and financial supports were very important aspects of community support. Families whose relative remained significantly compromised began to accept that their lives would never be the same and that the individual they once knew was forever gone.

Study limitations

The decision to interview family members individually may have impacted the identification of different family needs more than might have been identified by interviewing the family as a whole. Although the number of families not interested in participating was low (three of 28 family members), family members lost to attrition may have needs not described by study participants.

The study results may not be transferable, as participants shared individual stories that only they were experiencing. The large number of female caregivers may not reflect the reality of male caregivers. Although the sample included sisters and girlfriends as participants, a larger sample would provide a more complete description of their needs.

Implications for neuroscience nurses

This study demonstrated several implications for neuroscience nurses working in critical and acute care settings. Nursing support for families is crucial at a time of crisis. Nursing attributes described by family members included good listening skills, getting to know the family, demonstrating knowledge and competence in caring for the brain-injured relative, and establishing effective communication amongst all health care providers. As one father stated: "Gone are the days when the nurse says, 'You'll have to ask the doctor'—thank God!" Supporting the family's need for hope by identifying the patient's progress and validating the family members' feelings are key elements. Initiating these strategies early will create an atmosphere of trust with the family. Application of a social support framework for families may be important for nursing units to consider.

Allowing family members to stay with their relative, acknowledging their need for rest, food and sleep and answering their questions are critical factors in the first few days and weeks. Nurses need to reinforce to families that self-care needs to be a priority for them. Establishing a sense of trust, based on competence and knowledge of the patient, was critical in allowing the family to feel comfortable about leaving the unit. Families who were from out of town verbalized the feelings of lack of support from family due to distance and felt very much alone in the situation, and may require additional support.

Supporting the family in becoming more involved in the physical care of their relative was identified as important. Choosing the right moment, the right task and supporting them in undertaking the task increased the comfort level and confidence in the family's ability to become independent in caring for their relative.

Nurses played a central role in assisting the families during this critical time. Nurses need to recognize the value of their work and be proactive in becoming more involved in the family's psychological health. Family conferences are a valued mechanism for providing an in-depth discussion of the patient's status. However, they can be intimidating and over-

whelming for family members. Neuroscience nurses, with their knowledge of brain injury, should actively participate in these conferences in order to clarify terminology, ensure follow-through with goals of care, and provide support to families.

One of the challenges that the family faces is dealing with financial and legal matters for the patient, in particular when a Power of Attorney has not been identified prior to injury. Nurses should take the initiative to consult social work, or other relevant members of the inter-professional team who can support the patient and family in their recovery.

Transition from one level of care to another was often difficult for family members. Nurses in all receiving areas need to inform families about the next steps in the trajectory of recovery, as well as clarify misconceptions that may exist. Proactive discharge planning and acknowledging the differences in the units in advance of the transfer may facilitate the adjustment. In particular, patients who are transferred to a long-term care facility may require more support, as family members may see the transfer as the confirmation of the seriousness of their relative's injury.

This study was unique in the fact that sisters, brothers and girlfriends were included to participate. It is important for nurses to work collaboratively with them, while still respecting privacy laws.

Conclusion

This study described how family members experienced the injury in very dramatic and meaningful ways and reacted at an intensely emotional level. Although many factors impacted on the family's experience, families "lived the injury" in similar ways along the recovery, but differed in how they reacted and coped. The need to talk about their experience, to receive information about the injury and prognosis, to be supported by professionals in becoming involved in their relative's care and the assistance of the community in managing life were identified themes. The health care team can play an instrumental role in helping the family manage this difficult situation by recognizing the uniqueness of the family characteristics and by providing care and support that allows them to navigate this journey, even if the patient's recovery is limited.

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Appendix

Research and prompted interview questions.

Research questions

1. Can you tell us what it has been like for you since your family member was injured?
2. What has been most difficult for you since ____ (name) was injured?
3. What has been most helpful for you since ____ (name) was injured?

Prompt questions

- a) How do you feel about the information you've received regarding ____ (names') condition?
- b) How do you feel about the support you've received from staff?

- c) How do you feel about how your needs have been met?
- d) How do you feel about the services provided by the team? (physiotherapy, occupational therapy, social worker and other health team members)
- e) How do you feel about the support you've received from friends and family?
- f) How do you feel about your own involvement in ____ (name's) care?

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Role of the Critical Care Surgeon in Traumatic Brain Injury Jon C. Krook, M.D., F.A.C.S. Department of Surgery HCMC Case Presentation #1

55 y.o. female, MCA at highway speeds with no helmet

Was cut off by an auto and the bike down, was thrown from the bike

Was initially awake and talking to the first responders but.

All early management of the head injured patient is aimed toward limiting secondary brain injury

Avoid hypotension or hypoxia

Preserve oxygen delivery to the uninjured brain

Monro/Kellie Doctrine Brain CSF Blood Herniation

Supertentorial Herniation

Traumatic brain injury (TBI) is a leading cause of seizure, disorders, disability and death worldwide; regrettably, facilities for rehabilitation remain insufficient.

Needs inpatient care due to physical dependency, or need for specialist therapy equipment, safe environment, supervision or intensity of therapy, which cannot be provided in community.

McKay and colleagues [6] compared matched groups of severe head injury individuals who did or did not receive formal rehabilitation during their acute trauma centre admission.

An important study by Cope and Hall [8] compared 34 head injured people who had either been referred 'early' or 'late' to a comprehensive inpatient rehabilitation programme.

Traumatic brain injury (TBI) occurs when a traumatic event causes the brain to move rapidly within the skull, leading to damage. As illustrated in the poster (panel A), the event can be classified as either impact or non-impact, depending on whether the head makes direct contact with an object (impact) or encounters a non-impact force such as blast waves or rapid acceleration and deceleration (non-impact).

The frequency of brain injury is currently higher than that of any other disease, including complex diseases such as breast cancer, AIDS, Parkinson's disease and multiple sclerosis.

In contrast with this transient period of OH formation, severe CCI-injured rats showed a 250% increase in OH production, which was sustained above baseline for 90 minutes (Marklund et al., 2001).