

Needs of Family Members of Patients With Severe Traumatic Brain Injury

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Traumatic brain injury occurs in 500 000 persons each year in the United States; approximately 50 000 of these die before they reach a hospital. Of those who do reach a hospital, approximately 80% have mild traumatic injuries (Glasgow Coma Scale [GCS] score 14-15) and require little, if any, care in an intensive care unit (ICU). About 10% have moderate traumatic brain injuries (GCS score 9-13) and may be admitted to an ICU simply for observation. For

the remaining 10% (approximately 45 000 patients), who have severe traumatic brain injury (GCS score 3-8), rapid intervention and stabilization in an ICU can improve morbidity and mortality.¹

Initially, patients with severe traumatic brain injury are in an extremely unstable condition and may require surgery for removal of epidural and/or subdural hematomas and repeated computed tomography scans. They may need

intracranial pressure monitoring, hyperosmolar agents to control increasing pressures, and ventilator support.^{1,2} Although ICU nurses become accustomed to working in such crisis situations, the families of patients with severe traumatic brain injury may be overwhelmed by the patients' critical, constantly changing status. While the families experience the whirlwind of care, often without understanding what is happening, they must also address the possibility of their relatives' future dysfunction or untimely death.³ This time can be extremely stressful for these families.

Indeed, all admissions to an ICU are stressful for patients' families, but the sudden unexpected onset of severe traumatic brain injury, coupled with its unstable nature and strong probability of death, makes the families of patients with such injuries especially vulnerable. As Landsman et al⁴ reported, the severity of the injury may place demands on patients' families beyond the families' ability to cope. By following the vision⁵ of the American Association of Critical-Care Nurses (AACN) of advocacy for patients and patients' families (see shaded box), compassionate ICU nurses can alleviate the anxiety and concern of these families. Even though research findings indicate that staffing and time restrictions

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AACN Vision⁵

AACN is dedicated to creating a healthcare system driven by the needs of patients and families where critical care nurses make their optimal contribution.

Trauma

impinge on the care nurses give to patients' family members⁶ and some nurses consider interaction with patients' family members a low-order priority,⁷ appropriate interactions with the families are essential if nurses are to remain advocates for these patients and families and provide holistic nursing care.

Determining better ways to empower patients' families and meet their needs requires learning what they perceive their needs to be. The purpose of this qualitative descriptive study was to discover the needs of families of patients with severe traumatic brain injury during the families' experience in a neurosurgical ICU.

Review of the Literature

Providing care for patients' families arises from crisis theory, which states that the whole is greater than the sum of the parts: family adaptation or resiliency can affect patients' outcomes, both short- and long-term, either positively or negatively.⁸⁻¹² In the late 1970s, Dracup and Breu¹³ urged nurses to use Hampe's research findings,¹⁴ which identified the importance of meeting the needs of families of acutely or terminally ill patients. Soon thereafter, Molter published her study¹¹ of the needs of families of critically ill patients (Table 1). Molter and Leske refined Molter's randomized list of 45 family needs into the Critical Care Family Needs Inventory.¹⁷ The inventory clustered Molter's original 45 items into 5 categories:

1. support,
2. comfort,
3. information,
4. proximity, and
5. assurance.

The inventory was used throughout the 1980s and 1990s to quantita-

Table 1 Comparison of Molter's original findings of needs of families of critically ill patients with the needs of families of patients with severe traumatic brain injury*

Molter¹¹ Family needs of relatives of critically ill patients

1. To feel there is hope
2. To feel that hospital personnel care about the patient
3. To have the waiting area near the patient
4. *To be called at home about changes in the condition of the patient*
5. *To know the prognosis*
6. *To have questions answered honestly*
7. *To know specific facts concerning the patient's progress*
8. *To receive information about the patient at least once a day*
9. *To have explanations given in terms that are understandable*
10. To see the patient frequently

Mathis¹⁵ Personal needs of family members of critically ill patients with and without acute brain injury

1. To feel that hospital personnel care about my relative
2. *To be called at home about changes in the condition of the patient*
3. *To know exactly what is being done for my relative*
4. To be reassured that the best care possible was being given to my relative
5. *To have my questions answered honestly*
6. *To be told about how my relative was going to be treated medically*
7. *To receive information about my relative's condition at least once a day*
8. To feel accepted by hospital personnel
9. To feel there was hope
10. *To have specific facts concerning my relative's progress*

Engli and Kirsivali-Farmer¹⁶ Needs of family members of critically ill patients with and without acute brain injury

1. *To know the prognosis*
2. *To have questions answered honestly*
3. To be assured that the best possible care is being given to the patient
4. *To be called at home about changes in the patient's condition*
5. To feel that the hospital personnel care about the patient
6. *To have a specific person to call at the hospital when unable to visit*
7. *To know how the patient is being treated medically*
8. *To have explanations that are understandable*
9. *To know specific facts concerning the patient's progress*
10. To see the patient frequently

*Items italicized are need-to-know needs.

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tively identify family needs.^{10,15-23} In the AACN protocols for practice series on creating a healing environment, the booklet on the needs of patients' families⁹ has an annotated bibliography of 24 studies and a reference list of 122 other studies, all of which address the needs of, assessment of, interventions for, or satisfaction of patients' families. Clearly, the needs of families who have a family member in an ICU have been examined in many studies.

On the basis of the results of these earlier investigations, numerous researchers have attempted to address the needs of patients' families, with mixed results. For example, Appleyard et al²⁴ evaluated the effectiveness of a "nurse-coached" volunteer program to meet the needs of patients' families in an ICU. Volunteers provided information, comfort, and support to the families and notified the staff nurses of any family's concerns. At the conclusion of

the study, according to families' ratings, comfort was the only category with statistically significant improvement. The scores for support improved slightly, the scores for proximity remained the same, and the scores for assurance and information actually decreased. Even so, the families who received the intervention reported less anxiety and stated that they received better information than the families that did not receive the intervention reported.

In contrast, in a study on the effectiveness of a structured communication program, Medland and Ferrans²⁵ found that having families meet with a nurse about 24 hours after admission to discuss the patient's condition, giving them an information booklet, and then following up with a daily telephone call significantly decreased the number of telephone calls into the ICU, without affecting the families' perception of how well information was provided ($P < .05$).

Other studies indicated that assistive personnel can facilitate nurses' work with families. In one study,²⁶ family advocates, who worked directly with the families of trauma patients, helped the families throughout the hospital stay, as the families dealt with severe injury and death. The advocates received training in crisis intervention, grief counseling, and customer service, which helped them address families' concerns. Surveys of patients' families after the inception of the program indicated that the families felt greater satisfaction than families had indicated before the program began.

In recent years, investigators have broadened the search to retrospectively identify needs of patients'

families. In several studies,²⁷⁻²⁹ family members of patients who died were interviewed or filled out questionnaires. In the study by Malacrida et al,²⁹ 17% of 123 respondents thought that the information they received about the condition of their family member was neither clear nor adequate. In addition, 30% of the respondents were not satisfied with the information they received about the cause of the patient's death. Similarly, Abbott et al²⁷ found that 46% of respondents thought a conflict existed between healthcare professionals and the respondents. The respondents stated that healthcare professionals disregarded or ignored their input into treatment plans. Curtis et al^{28(p32)} strongly recommended that family conferences be used more effectively to improve "physician-family" and "nurse-family" communication in instances of impending death.

Families of patients with severe traumatic brain injury may be in a state of distress as they face the possibility of impending death for their loved one. In early studies of brain injury,^{15,16} the needs of families of patients with traumatic brain injury differed significantly from those of families of patients without such injuries (Table 1). The No. 1 need for the families of patients with brain injury was information about the patients' condition and what to expect. The families reported that they needed to have questions answered honestly and realistically. Other researchers³⁰⁻³² also found that the No. 1 need of families of patients with severe traumatic brain injury was information.

However, some investigators have recognized that some needs are still unmet, that the results of interven-

tion studies and recommendations might not be universally applied, and that deeper, as yet unrecognized, needs may exist. For instance, Dyer³³ noted that many studies are merely repetitions of the work of Molter and Leske and urged researchers to engage in new research. Burr maintained that use of a single measure alone does not provide an adequate assessment of all needs of families of brain-injured patients. She suggested that qualitative information could strengthen quantitative findings and determine if any needs existed that were not easily ascertained by quantitative means.³¹ Our qualitative study was designed to explore the needs of patients' families through individual interviews during the course of the patients' stay in the ICU.

Methods

Setting and Participants

We used an exploratory qualitative descriptive design and a convenience sample of family members of patients admitted to an 11-bed neurological ICU in a level I trauma center. After approval was obtained from the appropriate institutional review boards, family members who met the criteria were contacted by one of us (C.R.L.D.; see sidebar for an explanation of qualitative research). Consent forms, signed by the participants, provided an explanation of the project, the risks, the benefits, the time commitment, measures taken to ensure anonymity and confidentiality, and the voluntary nature of the study.

Inclusion criteria were (1) 1 family member of a patient with a diagnosis of severe traumatic brain injury who was at least 18 years or older, (2) the patient had a GCS score of 8 or less upon hospitalization; and (3) the

Qualitative Research

Qualitative research involves broadly stated questions about human experiences and realities and is conducted by using sustained contact with persons in their natural environments. The information gathered is rich and descriptive and helps us understand the participants' experiences. Researchers search for patterns and themes in the data rather than focus on testing hypotheses. An inductive rather than a deductive approach is used, leading to a narrative summary of the information that synthesizes the experiences of participants.

Purposes of Qualitative Research

- Explore and describe a topic that little is known about or gain insight about a particular group of patients or health condition
- Account for and illustrate quantitative findings to answer why and how questions
- Discover and explain phenomena
- Extend knowledge about a theory

Principles of Qualitative Research

- The focus is broad and holistic
- Data are usually oral or written responses to open-ended questions
- The wholeness of human experiences, in naturalistic settings, is studied
- The researcher is the data-gathering instrument
- Content analysis of the data involves examining the information and creating categories of data that are similar; analysis and collection of data occur simultaneously
- Data collection continues until no new information is learned (saturation)
- The number of participants (sample size) varies and usually is small; researchers continue to interview participants until no new information is obtained
- The term "rigor" is used instead of reliability and validity. Rigor is judged in 3 ways: credibility, auditability, and fittingness

Credibility means faithful descriptions or interpretations of a human experience that the persons having that experience would immediately recognize from those descriptions or interpretations as their own

Auditability means leaving a clear decision trail concerning the study, from the beginning to the end, so other researchers can follow the progression of events in the study and understand the logic of the researcher

Fittingness occurs when the audience views the study findings as meaningful and applicable in terms of the audience's own experiences

Phenomenology

Phenomenology (also called hermeneutics) is rooted in a philosophical tradition developed by Husserl and Heidegger. It is an approach to thinking about what the life experiences of persons are like and the process of learning and constructing the meaning of human experience through intensive dialogue with persons who are living the experience. Often the researcher will ask what it is like to live or experience something. Participants are purposively chosen because they are experiencing whatever the researcher is studying. Data are presented by using direct quotes that relate to a particular theme the researcher has identified.

patient was hospitalized in the neurological ICU for at least 24 hours.

Procedure

Initial data collection occurred in the privacy of a nearby waiting room. The same researcher (C.R.L.D.) interviewed all the participants to ensure consistency in the interviewing. On each of the remaining days of a patient's ICU stay, the patient's family member was asked to describe the family's needs and concerns and also was asked if any new needs had arisen. Subsequent interviews were conducted either at the hospital or by telephone, at the participants' convenience, building upon the trust developed during the first in-person interviews.

Recruitment of participants continued until saturation of the initial data occurred, with additional daily interviews of the original participants until their relative who was the patient died or was discharged from the ICU. Appropriate follow-up and probing questions were included as required. Interviews were recorded on audiotape and were transcribed verbatim; all identifying information was removed.

Data Analysis and Results

Seven family members of patients with severe traumatic brain injury (GCS score <8) participated in the study. Two mothers, a daughter, a father, a grandmother, a sister, and an uncle were interviewed during a 4-month period from January to April 2001. Their ages ranged from 41 to 61 years.

Although each participant had individual and unique situations and needs, content analysis indicated 4

Table 2 Overview of the needs of families of patients with severe traumatic brain injury

| Day of hospitalization | Need |
|------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | To know "Don't sugarcoat!" "If there is no hope, tell me there is no hope." |
| 2 | For consistent information "Each doctor said something different. And since not all of us were there together, each person heard something different." "... is it going to help or not?" |
| 3-6 | For involvement in care "I want to help, to be involved in [the patient's] care." "If there is anything we can do physically, tell us. The nurses haven't volunteered that." "Now I could have easily and gladly done that [the patient's bath]. But she [the nurse] told us to wait outside." |
| 7-22 | To make sense of the experience "It was a roller coaster. At first we didn't know how to handle it. One day we were told we needed to start thinking about donating [the patient's organs], and the next we were told to wait it out for 2 more weeks. Do you know what that does to you? It's like watching <i>ER</i> and hearing Dr Green tell Dr Carter to call it [the code], but he won't." Dealing with the death of patient: "We don't want her to be dragged on. We don't want to prolong [the patient's] life for the sake of her being a learning instrument." |

common themes (Table 2):

1. need to know,
 2. need for consistent information,
 3. need for involvement in care,
- and
4. need to make sense of the experience.

(In the following sections, the grammar of the material from the interviews was corrected slightly for readability.)

Need to Know

The most common phrase, heard from every participant on day 1 was "I just need to know." One participant stated that "a better relay system between physician and family would be much more helpful." Of the 7 participants, 4 had not been able to talk with the doctor yet when they were

interviewed initially, a situation that partially contributed to their lack of and need for information. Family members preferred to be told the truth about the patient's condition, even if the information conflicted with or compromised their need for hope. As one participant emphatically stated, "Don't sugarcoat! I can take it. Please give me some reality. If there is no hope, tell me there is no hope!"

Need for Consistent Information

Each participant spontaneously reported inconsistencies in information given to them by doctors, nurses, technicians, and other hospital staff by the second day in the hospital. One family member reported, "You get so much person-

ality from them that you are unable to know what is real and what is just opinion." Of the 7 participants, 5 expressed wishes that some kind of uniform, condensed information could be given by a single doctor to all of the family members, although the entire family was usually not present at one time:

Each doctor said something different. And since not all of us were there together, each person heard something different. When we came together as a family, it was very confusing and very problematic; we almost started fighting. We had conflicting information. More harm was done than should have been.

Another participant recounted the frustration of receiving different information from physicians:

One doctor said that [the patient] "absolutely could not hear anything." But then I go in there, and I notice that as I touch her arm and tell her who I am, the top line on the screen [heart rate] started to go up. I think she knew it was me; she recognized me and she was reacting to that. But that [the first] doctor said it wasn't possible. Then another doctor and I were talking and I told him about it and he suggested playing her favorite music for her on a little stereo. Now, is it going to help or not? Can she hear it or not? I want to do it if it is going to help her. This does not help me. I can take the bad news. Just don't tell us things that are not true and think that we need to hear happy things.

Need for Involvement in Care

On days 3 through 6 of the ICU stay, family members began to discuss their wish to participate in the care of their family member. Several participants expressed frustration at being restricted from the patient at times, and why they could not help with the care the patient required. As one participant stated, "It doesn't matter whether or not I can be in there, so much as it does [matter] why I can't be in there." Another family member remarked on this situation:

We just sit around, waiting. And we don't want to get in the way, but we want to be with our loved one as much as possible. If there is anything we can do physically, tell us. The nurses haven't volunteered that. I want to help, to be involved in [the patient's] care.

Two other participants also clarified the need related to what they could do for the patient. The first one stated:

If I had more instruction as to what to do by the bedside, I would do it. I am not afraid of that stuff [monitors, catheters, tubes]. But when I am told that nothing I do will make a difference, I just sit there and exist with [the patient]. And that is not what I am here to do. I am here to help [the patient].

Another participant remarked on this lack of information about patients' care by family members and recalled the nurse giving a bath to the participant's relative:

Now I could have easily and gladly done that. But she [the nurse] told us to wait outside. So I asked her if she would

come tell us when she was done, so that we could come right back into the room. But she forgot and we sat and sat and sat. I know that the nurses are busy, but we were just sitting there. I guess we have nothing better to do, but we want to spend as much time with her as we can. But even when we are in the room, we don't know what to do or what not to do. We just sit and stare at her [the patient] and each other. And what good is that doing [the patient]?

Need to Make Sense of the Experience

As new needs arose on subsequent days of hospitalization, previous needs for consistent and honest information remained unmet for the family members, compounding their emotional distress. They attempted to make sense of or to understand what they and their loved one had experienced. Some family members relied on their faith as they learned to accept that their loved one might not recover at all.

Three patients with severe traumatic brain injury had stays in the neurological ICU ranging from 11 to 22 days. One participant approached the doctors on day 8, stating, "We don't want her to be dragged on. We don't want to prolong [the patient's] life for the sake of her being a learning instrument." The participant's assertiveness, coupled with the patient's deterioration, resulted in a family conference on day 9. After the conference, mechanical ventilation was stopped, and the patient died 2 days later. The participant stated:

The biggest thing is the miscommunication. . . . But it would have helped if they could have talked through the procedures as they did them, instead of our having to ask. We would like to know why certain things are being done, what they hope to find out, what certain results mean. But when I have to ask, I feel intrusive. And then sometimes I get an answer that isn't English. I need an analogy, something to relate it to for normal [nonmedical] people. Another family member with a long-staying relative recounted what the experience had been like on day 12:

It was a roller coaster. At first we didn't know how to handle it. One day we were told we needed to start thinking about donating [the patient's organs], and the next we were told to wait it out for 2 more weeks. Do you know what that does to you? It's like watching *ER* and hearing Dr Green tell Dr Carter to call it [the code], but he won't. The family gets frightened, because it is too intricate for us to understand. I don't know if there is a right or wrong anymore, but I do know that God is the one in charge.

On day 22, the same participant spoke about the death of the patient: It's just a terrible thing and you hope no one ever has to go through this. It is scary. But you rely on your faith and on your family. . . . You know, everybody has to walk

through this some way. And we are trying to do that.

Discussion and Application for Nurses

Interviewing each participant each day of the patient's hospitalization entailed more than 60 interviews and provided a rich understanding of the stress that families experience. Additionally, when 4 of the 7 participants' relatives died, the data reinforced the seriousness of severe traumatic brain injury and the extreme need to support families of such patients during the patients' ICU stay.

The most pressing initial family need was the need to know, a finding that suggests family members want information about the diagnosis, the treatments, and the rationale for those treatments. This finding is simi-

lar to the results of earlier studies.^{15,16,30,31,34} Although families expect factual information from a single source, nurses and physicians know that all facts are not readily available during the early part of hospitalization of patients with severe traumatic brain injury and that there will not be just one person who can address all issues. Initial brain edema can mask diffuse axonal injury that will not become apparent until the swelling subsides. The patients may also have multiple other injuries that require additional time for identification. However, having healthcare providers meet with the patients' family mem-

bers early on and communicate what is known and what additional information is being explored would enable family members to begin processing the enormity of the injury and its continuing challenges. As the patients' families began to receive inconsistent information during the second and third days of the hospitalization, the family members discussed the need for consistent information. Other researchers^{27,29,31,32} have addressed the need of patients' families for consistent information, the conflicting information the families receive, and the families' dissatisfaction with the information given. In Burr's triangulated study,³¹ she used the Critical Care Family Needs Inventory and qualitative interviews to examine the extreme distress of family members of patients with

Continuity in nursing assignments could also decrease the families' anxiety. In addition, ICU nurses know that patients' family members may not assimilate all information at once but will need continual reinforcement over time. Families also need to have information presented in terms they can understand. As changes in the condition of a patient with severe traumatic brain injury are identified, with accompanying changes in procedures, the patient's family members need additional explanations and information. A comparison of the needs of families of critically ill patients originally described by Molter¹¹ with the needs of families of patients with severe traumatic brain injury^{15,16} indicates some form of the need to know was mentioned 6 or 7 times in each study (Table 1). Two of AACN's Values specifically support meeting these informational needs (see shaded box).³⁶ Clearly, information is important to alleviate families' distress.

After the first few days, the family members in our study voiced their need for involvement in the patients' care and were prepared to spend long hours at the hospital to support their relatives. The family members felt frustrated when they were not allowed to help with the patients' ordinary care. As Leske³⁷ pointed out, families can be beneficial to help alleviate patients' stress and improve patients' outcomes.

Items 1 and 2 from AACN's Values[®]

Advocate for organizational decisions that are driven by the needs of patients and families.

Act with integrity by communicating openly and honestly, keeping promises, honoring commitments, and promoting loyalty in all relationships.

Initial brain edema can mask diffuse axonal injury that will not become apparent until the swelling subsides.

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brain injury. She found that the unmet need of knowing was a main contributor to the families' intense feelings of anxiety and distress and that it remained a main contributor until the families obtained sufficient information to help with their understanding. Johnson et al³⁵ discovered that discussions and interactions with multiple attending physicians and different nurses every day resulted in inconsistencies and increased families' stress. Having a designated healthcare provider meet daily with patients' family members to provide updated information can lessen this stress.

Trauma

Certainly, nurses can include patients' families in basic care. Assisting with a patient's bath (if the relationship is appropriate) or other basic care would provide a sense of inclusion and increase the family member's understanding of the gravity of the patient's situation. It would also help prepare family members for their upcoming care-giving role or help them realize that they may need to think about an extended-care facility when the patient is discharged from the ICU. Such an experience would benefit both patients and family members.

A close look at the needs identified in our study indicates that the families' initial needs for information continued over time. Although the families reported that their needs for information remained unmet, they asserted themselves. First they tried to obtain information, and then when they realized that the information was not consistent, they tried to move into an adaptive behavior: providing care for their family member to validate the information they had and seeking additional information. When patients remained unconscious for a long period, and had an extremely poor prognosis, the patients' family members attempted to put the experience in perspective and to reach closure. (Current family members of patients with severe traumatic brain injury have reviewed the experiences and interpretation reported here and have agreed with our findings.)

As the family members in our study reviewed their stay in the ICU, they reflected on the overall experience, trying to make sense of it all, reaching for closure. On the basis of information and suggestions they provided, the recommendations of

Table 3 Collaborative intervention plan for families of patients with severe traumatic brain injury*

| Intervention | Steps in the intervention |
|-----------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Initiate information protocol | Meet with the patient's family when the patient is admitted to the hospital Provide current information about the extent of the patient's injury and prognosis Arrange to meet the family again immediately after the patient's condition is initially stabilized Allow the family to see the patient immediately, regardless of the patient's condition Arrange support through social worker or pastoral leader Provide a beeper or telephone number for necessary updates Provide booklet with information on severe traumatic brain injury |
| Arrange daily time for family briefing | Have the family designate a spokesperson to receive information and to relay that information to other family members Reinforce understanding and clarify misconceptions Review the information in the booklet on severe traumatic brain injury Be professional in discussions with the family; provide accurate information, suppress personal bias, and support the family in their decisions |
| Be sensitive to the families' individual characteristics | Be sensitive to family issues, feelings, and religious considerations; differences in educational and cultural backgrounds; and the dynamics of divorced or estranged families |
| Validate the family's feelings throughout the patient's stay in the intensive care unit | Help family members draw upon their personal beliefs and practices Recognize that the major source of frustration is the patient's unstable condition and uncertain outcome |
| Encourage continuity of information support for patients' family members | Provide in-service training for staff members of the neurological intensive care unit |
| Provide comfort to patients' family members | Use hospital volunteers, social workers, or family advocates to provide comfort measures |
| Meet the families' need to be involved in the patients' care | Allow the family to assist with the patient's basic care |

*Based on suggestions from patients' families, recommendations of earlier studies,^{22-25,34} and Leske

earlier intervention studies,^{22-25,34} and the work of Leske,⁹ we recommend simple interventions to empower patients' families and meet these needs (Table 3). Nurses also need to remember that individual family needs are subjective and require individualized attention and support. Harvey^{38(p206)} recommended a "strong multidisciplinary approach and a unit culture that encourages keeping the family informed."

Johnson³⁹ agreed and also recommended that nursing and medical students be acculturated into the notion of family-centered care and practice.

Implications for Evidence-Based Practice

Since Molter's seminal work¹¹ on the needs of families of critically ill patients, ICUs have undergone many changes. New diagnostic pro-

cedures and technology enable staff to treat patients more aggressively, with improved outcomes; most hospitals now have one-patient rooms to provide more privacy; many hospitals have lenient visiting hours for patients' immediate family members; and waiting rooms are more convenient in size, decor, and proximity to patients. In order to further improve ICU experiences for patients' families, the AACN protocols for practice series includes the booklet *Family Needs and Interventions in the Acute Care Environment*.⁹ Additional articles have reinforced the value of the AACN series.⁹ Yet, with all these improvements and materials, nurses continue to recognize that needs of patients' family members are not being met, as evidenced by numerous new studies that continue to describe these needs.

A closer scrutiny of the results of studies on the needs of families of patients with traumatic brain injury may indicate nurses have overlooked an important concept, namely, empowerment of patients and patients' families, and have continued to follow an older, paternalistic model in which healthcare professionals take charge. Nurses may pay lip service to patient-centered care and think their studies and interventions have been carried out to support patients' families but may not recognize why the top needs of patients' families consistently include the need for information (Table 2). Healthcare issues of today, such as informed consent, do-not-resuscitate orders, and managed care, require including patients' families in decision making for the care of the patients. Without ade-

quate information, families cannot determine the correct care for their family member and consequently feel powerless and out of control. Williams^{40(p100)} defined empowerment as "the creation of an environment in which individuals can behave as responsible adults, and where decision making is made at the point where the knowledge is greatest." Empowered families of patients with severe traumatic brain injury, armed with information, can work with healthcare providers to achieve quality care.

Limitations

The focus of our study was strictly the needs of families of patients with severe traumatic brain injury during the patients' ICU stay. We did not evaluate the families' home dynamics or the stresses that accompany disruption of regular routines, financial disruption, or other lifestyle changes. Qualitative research, with small sample sizes, can provide insights about a particular group of patients or health condition and can illustrate quantitative findings, but it is limited in its generalizability.

Recommendations for Further Research

Using the concept of empowerment of patients and their families⁴⁰ and Leske's contribution⁹ in the AACN protocols for practice series, researchers should focus on ways to meet the needs of patients' families for information and ways to incorporate the families' input in decision making about the patients' care. Investigators should evaluate the effectiveness of the interactions, by working with families, rather than merely examining family interventions.⁴¹

Evidence-based practice requires healthcare providers to identify interventions that lead to intentional, systematic improvements in informed decision making by patients' families, decrease the families' stress, and improve the patients' outcomes.

Conclusions

We identified specific needs of families of patients with severe traumatic brain injury during the patients' stay in the neurological ICU: the need to know, the need for consistent information, the need for involvement, and the need to make sense of the experience. On the basis of the results of earlier intervention studies,^{22-25,34} suggestions from the families in our study, Leske's contribution⁹ to the AACN protocols for practice series, and AACN's Values,³⁶ nurses can alleviate the stress of patients' families by providing information and ways for the families to be involved in the patients' care. Such a model of holistic care, based on evidence, will validate the role of patients' families during patients' hospitalization and improve outcomes for families and, possibly, for patients.

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