

Families' Perceptions of Surgical Intensive Care

Timothy G Buchman, PhD, MD, Shawn E Ray, RN, BSN, CCRN, Murray L Wax, MD, PhD,
Joan Cassell, PhD, David Rich, BA, MCP, Mary Ann Niemczycki, PhD, MMR

Optimal delivery of surgical critical care, and end-of-life care in particular, remains a formidable challenge. Patients and health care providers are often at odds at the end of life, struggling with moral, ethical, and spiritual dilemmas. The critical care nurse often assumes the role of "go-between," coping with the failure of surgeons and intensivists to negotiate smoothly the transition from cure to comfort care. Although the critical care nurse is invested in the rescue imperative, she is the person who most frequently establishes common ground with family members. A longterm goal of this research is to develop and implement interventions and then measure family members' and caregivers' approval of how well the dying process has been handled. To design interventions, it is necessary to describe the perceptions of families with respect to the care of critically ill surgical patients.

We selected focus group methodology to compare and contrast perceptions of families of survivors with those of bereaved families to determine the extent to which patient outcomes determined families' perceptions of care. Specific objectives included determining the:

- overall perceptions of critical illness and critical care;
- relationships between family member and significant others and caregivers;
- nature and quality of family interactions with physicians, nurses, and other surgical intensive care unit (SICU) staff members;
- nature and quality of communication with physicians and nurses in the SICU; and
- perceived strengths and weaknesses of the SICU.

METHODS

Focus group analysis was selected as an important methodology for hearing from family members (and signifi-

cant others) of SICU patients. The group setting is more comfortable than one-on-one interviews. In focus group discussions, the comments of one group member help to stimulate memories and reactions from others. When one person recalls experiences, it enables others to relate to that experience, making it easier for them to speak out. Focus groups welcome diverse comments, allowing researchers to collect a wide range of opinions. Findings can then be objectively analyzed to reveal perceptions about common experiences.¹

To address our objectives, a comparative study design was used. Six focus groups were conducted with patients' family members and loved ones at Barnes-Jewish Hospital in St Louis, MO, between December 2001 and February 2002. Three groups were composed of relatives of SICU patients who did not survive ("nonsurvivor"), and three were made up of family members of SICU survivors ("survivor"). Participants were recruited from a list of family and close friends of patients who had been treated in the SICU between 6 and 18 months before the focus groups. Although invitations were extended to family members of both genders, those who chose to participate were predominantly female. Each focus group included four to eight participants.

Participants in the nonsurvivor groups included 11 African-Americans (10 women and 1 man), and 6 Caucasians (5 women, 1 man). The survivor groups included 13 Caucasians (11 women, 2 men), and 6 African-Americans (5 women, 1 man). All but one of the participants were family members of the SICU patients; one participant in the survivor group was the patient's fiancée.

The patients were predominantly emergent admissions. Four of 17 patients who did not survive came to the SICU after a prolonged illness; 13 were emergency cases admitted through the emergency room or transferred from other hospitals. Two of the surviving patients came to the SICU after elective surgery or other treatment at Barnes, or other hospitals; 17 were emergency cases admitted through the emergency room or transferred from other hospitals.

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From Washington University School of Medicine and The Research and Planning Group, St Louis, MO.

Correspondence address: Timothy G Buchman, PhD, MD, Box 8109, 660 South Euclid Ave, St. Louis, MO 63110-1093.

opinion research company located in St. Louis, MO. The moderator's guide was designed by all authors of this study. But the focus groups themselves were conducted in a hospital conference area by the two professional moderators, David Rich and Mary Ann Niemczyk, of The Research & Planning Group.

The study was reviewed and approved by the human studies committee of the Washington University School of Medicine. Participants were offered light refreshments and a \$60 honorarium for their time. No participant indicated undue stress from participation in the study or requested any followup intervention. On the contrary, most spontaneously expressed gratitude for the opportunity to comment on their experiences.

Although the opinions expressed in properly conducted focus groups can be considered representative, focus group research results are not appropriate for making statistical comparisons.² For this reason, the descriptions used in the results section should be considered approximate and comparisons interpreted as qualitative, not quantitative.

RESULTS

(In this section, verbatim responses given by focus group participants are presented in *italics*. All other comments represent summary evaluations by the investigators.)

The SICU and critical care

Few family members appear to be prepared for the ICU experience. Family members were asked about their impression of an SICU or ICU before the patient was admitted. They were also asked what comes to mind when seeing or hearing the words *critical care*?

Responses were similar across survivor and nonsurvivor groups. Regarding the SICU, families described a place for "*Life-threatening (conditions)*" in which "*Everyone seriously ill, was on their deathbed. . . .*" Critical care was thought to be related not only to even greater severity of illness, but also to the need for constant, invasive monitoring. Families believed that staff were "*Watching over [the patients] 24 hours a day*" using "*tubes, wires, monitors.*" Critical care was perceived as "*more intense and life-threatening*" than the SICU. Notable among the responses is attention to the status of the family member, and general neglect in the descriptions of the SICU and critical care of what the professionals are trying to do to change that status.

Relationship between the patient and family member

Most patients were admitted to the SICU as emergency cases and family members assumed responsibility for decision making regarding their care as soon as they arrived at the hospital. When patients had been ill for an extended period, family members frequently had accepted the role of caregiver and decision maker long before the patient was admitted to the SICU.

Family members felt an obligation to accept responsibility for life-and-death decisions. Virtually all believed that family members, especially those who had been caring for the patient, should have the final word when it comes to making life-and-death decisions and carrying out the wishes of the patient. Family members often shared responsibility with other family members or turned to hospital staff for support. "*My family. . . very close family. Whenever there is a decision to be made, we all come together. . . we all have something to say about it. . . and we all come to agreement as to what is to be done,*" explained one family member. Another family member commented, "*The doctors were wonderful, they reinforced our decision [to remove life support]. . . .*"

Family members of those who did not survive generally believed that the hospital staff were very helpful in explaining the situation. "*Doctors, they came in groups. . . would discuss what each of them thought and make a decision. When they weren't there, the trauma nurses would. . . make the decision. I was very impressed by them,*" stated the mother of a trauma patient. Families of those who did not survive were also impressed with the time the family was allowed to be with the patient and to make their decision. "*They gave us our own private room for the family so we wouldn't have to sit out in the waiting room. We had our own room next to my son. They got me a tall chair so I could sit right by his head and face. . . they would hug you. . . .*" Many expressed their appreciation for being allowed to spend as much time as they wished with their loved ones at the end.

Impact of SICU experience on patients' families and loved ones

Relatives of all SICU patients relied on information provided by doctors and nurses, but those who lost loved ones seem to have relied more on nurses for information. As one daughter of a patient who died stated, "*If I could speak to just one person every day, it would be the nurse.*" A wife of another patient reported, "*The nurse is most pre-*

pared to give you the most relevant updates." Another verbalized, "The nurses in the ICU did not give us false hope; they told us he was going to die." Nurses' constant attendance to the patient's needs and to the emotional support of the family throughout the end-of life decision-making process likely results in this perception.

Family members of patients who did not survive often reported that they never spoke to or met the surgeon, and some stated that their telephone calls were not returned. Others reported that they had not met the surgeon until they made a specific request to do so. On the other hand, they were impressed with the care provided to their loved ones by the SICU critical care staff. In fact, those who lost a loved one in the SICU seemed more impressed than relatives of survivors with the care received by SICU patients.

Family members of nonsurvivors seemed to be more critical of the doctors and other SICU staff. A few relatives complained about lack of concern by doctors who did not take the time to learn about the patient, or nurses who left patients uncovered and exposed. As a daughter of a patient explained "They could improve on privacy. Everyone could see my mother when they walked past her room."

Families of those who did not survive were more likely to feel that everything that could have been done was done; they tended to focus on the excellence of the care provided to their loved ones. Family members of survivors were more likely to comment on how friendly and concerned the SICU staff was about patients and their families. One daughter of a patient stated, "one particular nurse, she paid special attention to my father. . . she shaved and cleaned him up. . . kept a close eye on him. . . I really appreciated that." One family member commented: "The nurses not only knew the patient, they wanted to know about you," and yet another, "The nurses were concerned about me; they wanted me to take care of myself."

Interactions with the physicians, nurses, and other SICU staff members

Family members tended to feel good about the care given to their loved ones, but family members of those who survived are more likely to remember the names of the physicians and nurses involved in the care of their loved ones. Very few of those whose loved ones died in the SICU remembered the physicians' or nurses' names.

Most family members of survivors believed the surgeon was in charge of the patient in the ICU, but those

who lost loved ones in the SICU were less sure of who was in charge. Few recalled seeing a surgeon, and several believed that it is the nurse who is really in charge. Although most believed that the physicians kept them sufficiently informed about the patient's condition, some family members of patients who died in the SICU reported feeling abandoned by the surgeon after the operation. One wife of a patient spoke of her experience: "We lost contact with the original surgeon. We felt abandoned by him, but thank God for the ICU physician. I later called him and he apologized. He said he was still connected to the case."

Most family members had positive experiences with the nurses who cared for their loved ones. They described the nurses as compassionate, concerned, and informative. Others expressed concern that the nurse-patient ratio was too low. "If they could have one to three patients for each nurse. . . maybe that would be better." "I think three (patients) would be a lot." In our SICU, the standard ratio is two patients for each nurse. Although this standard is typical for the US, it is lower than other countries (such as New Zealand), where a 1:1 nurse-patient ratio is standard.

Communication with physicians and nurses in the SICU

Family members experience a wide variety of feelings during conversations with doctors and other staff. Family members of those who survived recalled feeling well informed and relieved, or frustrated and confused. One son of a patient, who felt informed, stated, "I get the impression that there really isn't a policy on what information is provided to family and how it's provided, it's 'catch them when you can.' I know every patient and every situation is different, but if you ask enough questions often enough, you'll get as much information as you probably want." One relative of a patient commented: "There were two doctors. One female doctor would talk to me; would make any sense to me. . . like a human being. When she came back. . . next morning. . . I'd tell her I was lost. . . she would tell me what was going on. . . (Other) doctors would give me some far out answer. . . brushed me off. She took the time to say. . . if we do this. . . this is going to make him better. . . we've done this overnight. . . or it was a good night or a bad night. . . I think she was a doctor." Still, another family member commented regarding the nurses, "Nurses would sit down with me and talk, not act like one foot out the door." Other frustrated family members commented,

"I never saw a surgeon" (this comment was repeated by four individuals representing different families). "I would get a different version, depending on who I talked to." "I couldn't be there. . .they never called. . .they never got messages." "I never saw my mother's surgeon until I took her to his office after she was home."

For those who had lost a loved one, the memories were often hard. They remember that the doctors asked them questions and that they had to make life-and-death decisions regarding the patient. They felt anxious, nervous, frightened, and aggravated during these conversations. "The doctor asked the first question. . .he informed us of his [chances for] recovery. We never got a straight answer, I didn't like it. If you're not going to do it soon, don't say you're going to do it," stated one family member. Still another comment from the wife of a patient who described her experience:

We kept going round and round about my husband. . .he was on a ventilator. We were concerned about when he would be taken off the ventilator. That question came up almost every day. How he was doing and the doctor would get feedback from the nurse, and say we don't think he is going to manage on his own. He never really did wake up after surgery. They would always want to "wait until tomorrow" to see if he would wake up. There was talk of a tracheostomy being done and that just went on for days on end until. . .we decided that he should no longer be on the ventilator. He never woke up after surgery because of all the medications he was on and the interactions.

Family members believed that the nurses provided good care to the patients. Most did not recall the nurses' names, but they described them as compassionate, concerned, and informative toward the patient and family members. "She explained the different machines, the monitors, what they meant. . .explained the dialysis." "Wonderful, they would talk to my son as if he were awake, and would explain to us what all the machines meant." "Nurses do the "hard" work. They would be very calm and talk to you and reassure you." "They treated my mom like she was their mom."

Although everyone thinks that it is important for SICU staff to agree before they talk to the patient's family, some relatives of patients who died in the SICU reported disagreements between the doctors. "We would get different views from different doctors" describes one family member. Another stated, "Some disagreed about

what needed to be done (brain and lung surgeons.)" These disagreements tended to raise more questions for family members struggling to understand what was going on. Relatives of survivors do not recall disagreements between hospital staff.

Relatives of survivors and nonsurvivors agreed that surgeons should not give any false hope, nor should they put a timeline on the patient or say when they should live or die either. As one family member stated, "I can deal with the chance of not making it, but not false hope," and another, "Don't put a time limit on it." Most also agree that negative information should come from doctors, but that it is important how they say it. One family member elaborated, "Straight out, don't beat around the bush. . .don't try to cover anything up, just tell us just the way it is. You could say one word and change the whole meaning, make the person think that maybe there's a chance, but if there's not a chance, tell it."

Doctors were criticized most often for failing to give straight answers on the one hand, and for being too abrupt or callous on the other. Although all agreed that doctors and surgeons give the most knowledgeable information regarding the patient's condition, many believed that nurses are better at helping family members understand what is happening. A daughter of a patient stated, "The nurses came down to where you could understand, not the doctors." The wife of a trauma patient also explained, "I trusted the nurses to bring it down to my level. The doctors would discuss the CT scan findings with me, but the nurses would say, 'I opened the blinds and he flinched his eyes.' That was exactly what I needed to hear!"

Lack of ongoing communication was the weakness mentioned most often by family members of those who did not survive. Virtually all felt there is a need for more and better communication in the SICU. "Better communication between the surgeons to the ICU," was mentioned by at least three nonsurvivor family members. One way the SICU staff can improve communication is by becoming more sensitive to the different communication styles or levels of those with whom they interact. Identifying those who are having communication problems and bringing in someone such as a social worker or chaplain to assist in accessing physicians and getting explanations can improve the ICU experience for many.

Strengths of the SICU

Family members agreed that their loved ones were receiving the best possible medical care available. This was

not just "technical" care. They believed the nurses were there not only for the patients, but also for family members. The nurses made them as comfortable as possible and they (along with other SICU staff) make every effort to answer questions and keep family members informed. Some felt nurses are more honest about the patient's condition and better able to put things in laymen's terms than doctors. "*The nurse in the ICU was the only one that did not put all hopes up. . . she gave us the reality that he was not going to make it and this is how I want to approach you with it*" was described by the daughter of a patient. Another family member explains, "*The nurse actually stayed right there by the door in case somebody needed to talk. The doctor said she did not have to stay. . . but she did anyway to help the family.*" Most of the family members of those who did not survive believed that everyone in the SICU showed compassion by comforting and supporting them. They felt that the patient was given the best possible care, and they appreciated the time they were allowed to spend with their loved one.

Suggested improvements for the SICU

Focus group participants voiced that families and friends of those in the SICU need to know what to expect. They should know that it is all right to ask questions if they need information. Other information such as guidelines for visits and information on health directives should be made available as soon as they arrive in the SICU. This sort of information is currently included in a booklet available in the SICU waiting room, and is now more consistently distributed.

The consensus among family members of survivors and nonsurvivors was that the waiting room needs to be larger, should have more comfortable chairs, refreshments, restrictions on children, and better housekeeping. Families of nonsurvivors also wanted a larger SICU with more privacy and more nurses to provide better care; they would like to see more people working in the SICU. Survivor family members recommended that SICU permit e-mail updates, recognize the decision-making role of family members, and offer special parking arrangements for families of SICU patients. Both groups felt that some nurses, doctors, and hospital staff members need to do a better job in communicating with family members and loved ones. Relatives of both survivors and nonsurvivors suggested that communication could be improved by designating one hospital staff member as a primary communicator with the family of

each patient. There is no doubt that some families received "mixed messages." Review of those cases suggested that surgeons and critical care staff held complementary, but incongruent, opinions about condition and prognosis.

Perspective and recommendations

Although focus group discussions encourage the expression of a wide range of opinions, they are most useful in revealing common threads that run through the shared experiences and perceptions of group participants. This focus group study revealed that relatives of patients who came to the SICU for a variety of reasons, with a variety of outcomes, tended to describe a common experience. On the whole, these focus group participants were aided and comforted by the SICU experience regardless of the medical outcomes for their loved ones.

Some differences between the experiences of relatives of survivors and those of patients who did not survive emerged from the discussions. Perhaps surprisingly, family members of those who did not survive tended to focus on the excellent care provided to their loved ones. They seemed to take comfort in knowing that they received the best medical care possible and that everything that could be done was done. They also seemed more satisfied in this regard than the relatives of survivors. Many of these family members of nonsurvivors were working to put the pain of the SICU experience and their ultimate loss behind them. They did not recall names or other details, and preferred not to dwell on negatives such as poor communication by surgeons.

Relatives of survivors tended to focus more on how well they and other family members were taken care of by the nurses and other SICU staff members. As the conversations in each focus group developed, discussion turned to the actions of the SICU staff. Recollections of nurses and nursing care with descriptions such as "*personable and friendly,*" "*more informative than the doctors,*" "*they changed him constantly. . . kept him clean. . . they were good to me,*" were mentioned by families with positive experiences. These families spoke of how the nurse's words and actions made a difference. Family members of survivors were also more likely to remember the names of the doctors and nurses who took care of their loved ones and helped to comfort them. They also seemed to be more critical of the communications from doctors and the care received by patients.

Both groups identified the waiting room and commu-

nication as areas that need to be improved. The waiting room issues are relatively clear-cut. Addressing the communication issues will be more challenging. Most ICU physicians seem to be trying hard to make themselves available to family members, but surgeons appear more elusive. It seems no accident that the relatives of survivors appeared to have more contact with surgeons and other doctors than relatives of those who died.

It is possible that poor communication is attributable in part to sociocultural factors, such as race, gender, and education of the family member. Despite best attempts to match focus group participants for ethnicity and education, survivors' relatives in our focus groups were predominantly Caucasian and articulate. Family members of those who died in the SICU within our focus groups were more likely to be African-American and less articulate. Our impression was that better educated, articulate family members might simply be more demanding or else more effective in accessing surgeons or other physicians. Those who are less educated or lack confidence might find it easier to communicate with nurses. Nurses are generally more available at the bedside to meet the needs of patients and families. Families might also feel more comfortable talking with a nurse because of a perception of sharing his or her social class to a greater extent than they share the social class of a physician.³ This study indicated that nurses frequently make an effort to reach out to families. Kleiber and colleagues⁴ suggested that because of the variability in emotional responses, nursing interventions to assist families must be directed toward individual family members' changing needs throughout the hospital stay. Providing anticipatory guidance in relation to the need for frequent and updated information can also make a difference in helping family members understand what to expect.

Way, Back, and Curtis⁵ recently reviewed the many reports that have focused on end-of-life discussions in critical care areas. The importance of managing family conferences in which end-of-life issues are presented and discussed cannot be overstated, and analyses suggest that much more structure can be applied to these pivotal interactions.⁶ Fortunately, the majority of patients who receive critical care survive. Our focus group analyses suggest that there are more similarities than there are differences among the experiences of survivor and non-survivor families, and that more effective communication would serve all.

SUMMARY

Similarities and differences of opinion among families of SICU survivors and nonsurvivors

Shared opinions

- Need for improved communication.
- Need for more comfortable family waiting areas.
- Nurse, not physician, is the primary communicator.
- Patients received high-quality medical care.

Nonsurvivor family opinions

- Physicians focused on a physiologic view of the patient; a more holistic perspective is preferred.
- Prognoses made by different physicians were sometimes inconsistent; the inconsistency was troubling to families.
- Surgeons were less often present or available; there was greater dependence on nurse and critical care physician staff for information.

Survivor family opinions

- More frequent updates on condition were desirable, but need not be face-to-face. Use of email was suggested.
- Need for greater respect of family authority in care decisions.

Author Contributions

Study conception and design: Buchman, Wax, Cassell, Rich

Acquisition of data: Rich, Niemczycki

Analysis and interpretation of data: Buchman, Ray, Rich, Niemczycki

Drafting of manuscript: Buchman, Ray, Rich, Niemczycki

Critical revision: All authors

Obtaining funding: Buchman, Ray, Wax, Cassell

Supervision: Buchman

Appendix

Executive Group, Surgical Palliative Care Task Force, Division of Education American College of Surgeons

Geoffrey Parker Dunn, MD, FACS, Erie, PA, Series Editor

Timothy G Buchman, PhD, MD, St Louis, MO

Karen Jean Brasel, MD, FACS, Milwaukee, WI

Joseph M Civetta, MD, FACS, Farmington, CT

Alexandra M Easson, MD, FRCS(C), Toronto, Ontario

Daniel Benjamin Hinshaw, MD, FACS, Ann Arbor, MI

Joan Lynn Huffman, MD, FACS, Upland, PA

Robert Scott Krouse, MD, Tucson, AZ

K Francis Lee, MD, FACS, Springfield, MA

Laurence Edward McCahill, MD, FACS, Alhambra, CA
Robert Alan Milch, MD, FACS, Buffalo, NY
Anne Charlotte Mosenthal, MD, FACS, Newark, NJ
Albert Reed Thompson, MD, FACS, Little Rock, AR

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