

The State of the Science: Decision Making in the ICU

Making End-of-Life Decisions

Each family is different, creating challenges when the time comes to make treatment decisions.

About 20% of deaths in America occur in an ICU. Researchers at the University of Rochester School of Nursing, led by principal investigator Judith Gedney Baggs, PhD, RN, FAAN, studied end-of-life decision-making in four ICUs (medical, surgical, burn-trauma, and cardiovascular) in an academic teaching hospital in the Northeast. Past studies have tended to assume all ICUs are alike in managing patient deaths. This study found remarkable incongruities and variations in the culture of the ICUs, which influenced how end-of-life care was discussed and managed.

Using ethnographic techniques of observation, semi-structured interviews, and family meetings, the nurse researchers collected and analyzed narrative data to make comparisons among patient and family cases, groups of different clinicians, and the ICUs themselves. The investigators presented their findings in five papers delivered in a symposium on October 7, 2004, at the National Congress on the State of the Science in Nursing Research in Washington, DC.

"I feel like I sentenced her to what she's got now, as though she were a prisoner," lamented a husband whose decision to continue life-supporting treatment meant his wife was on a ventilator. This perspective was an example of what investigator Mary T. Dombeck, PhD, DMin, called "depersonalizing." It occurs when technology limits the patient's capacity and expression of personhood, including participation in the decision-making process. Another form of depersonalizing was what Dombeck called "technology as routine," when care providers pay attention to the technology and speak over the patient, as though he or she didn't exist.

Families play an important role in ICUs when decisions need to be made for a patient who can no longer make treatment decisions. Family members tend to fall into what Jill R. Quinn, PhD, RN, CS-ANP, called "informal roles," such as primary decision maker, out-of-towner, spokesperson, and protector. Each of these roles brings a unique complexity to the interchanges between family and clinicians during communications about the patient's worsening condition and what should be done. For example, the out-of-towner family member tends to be more removed from the patient's illness and thus may need more time to come to terms with the prognosis. The spokesperson, a more formal family role, is often viewed by physicians and nurses as the person in the family with whom to communicate, who will best represent the interests of the patient. However, according to Quinn, "The problem often is that there is not a family spokesperson, but rather a spokes group." As much as clinicians might prefer a single member of the family to act as spokesperson, they should realize that this will be impossible for many families.

In a third paper, Baggs and coauthor Madeline H. Schmitt, PhD, RN, FAAN, FNAP, tackled the question of physicians' roles and rules in decision making. The average American might be surprised to learn that doctors in ICUs are from numerous specialties (e.g., intensivists, surgeons, palliative care specialists) and follow a myriad of formal and informal rules in their relationships with each other as well as with the patient and family. The researchers quoted a family member who said, "It seems funny to have two attendings, and they're both talking to the family, and they're not talking to each other." The result can be confusion for the family when inconsistent messages demonstrate that physicians are not coordinating the patient's medical care.

Sally A. Norton, PhD, RN, examined the timing of stopping life-sustaining treatment and found that family members and clinicians can be on very different paths toward decision points. When families and providers are in timing harmony, which Norton termed a "synchronous trajectory," they simultaneously reach the point of being ready to stop treatment. An asynchronous trajectory occurs when a family member is at a different place in the path toward

decision making, that is, is not in concert with the rest of the family or with the health care team. In the latter instances, clinicians talk about giving time or slowing down or, conversely, pushing along toward decisions. Norton concluded that time and timing are important dimensions of end-of-life decision making, and that recognizing the importance of timing can help the health care team work successfully with the family.

The final paper, by Craig R. Sellers, MS, RN, APRN, focused on advance directives – whether patients had an advance directive before admission to the ICU, whether the advance directive was consulted when the patient was unresponsive or otherwise unable to communicate, and whether there were problems deciding what treatments to use or to withdraw. About half the patients in this study had completed an advance directive before hospitalization. However, difficulties in decision making occurred for patients with and without advance directives. This study suggested that advance directives alone, without additional dialogue and clarification, do not adequately prevent disagreements at the bedside.

Overall, what does this large body of research mean to patients, families, and clinicians who are facing end-of-life issues in ICUs? Baggs summarized a few key points. First, ICUs are vastly different, differing in culture, style, expectations of how care will be given and decisions negotiated, and the degree to which the personhood of each patient will be safeguarded. Second, clinicians need to understand that every family will bring unique features to the situation. Family members will assume various informal roles and may be on different pathways in coming to terms with the finality of the patient's condition. Third, advance directives don't solve all problems and may be insufficient in preventing disagreements about treatment decisions. Because ICUs are a common setting for end-of-life decision making, the study findings are important for both health professionals and the American public. - *Virginia P. Tilden, DNSc, RN, FAAN, reporting.*