Communicating and Connecting With Patients and Their Families

By Cindy L. Munro, RN, PhD, ANP, and Richard H. Savel, MD

Connection with patients and families is an essential part of critical care. Dr Brene Brown, in her recent book, Daring Greatly: How the Courage to Be Vulnerable Transforms the Way We Live, Love, Parent, and Lead, sees connection to others as a central truth of human life: “The surest thing I took away from my BSW, MSW, and PhD in social work is this: Connection is why we’re here. We are hardwired to connect with others, it’s what gives purpose and meaning to our lives, and without it there is suffering.” Our physical connection with patients during clinical care is intimate and focuses on assisting them in meeting the challenges of critical illness. We also connect with patients and their families through our communication with them.

Communication with families is sometimes viewed as a means to an end. It becomes a mechanism for getting things done—a way to make difficult but necessary decisions about care. In our health care system, families are expected to act as surrogate decision makers for critically ill patients who are often unable to speak on their own behalf. This communication between providers and families is a delicate dance, and many complex issues are enmeshed in the relationship.

Clinicians have their own beliefs about patient autonomy, best care, and family responsibilities. Family members vary in their knowledge of patient wishes, their willingness to act, and their understanding of the surrogate role. Relationships within families vary, from highly supportive to overwhelmingly dysfunctional. Preferred decision making styles run the continuum from passive to assertive. The stakes in decision making communication are high. We recognize the crucial effects of health care decisions on the patient, the family, and the clinicians, but do not always appreciate the consequences these decisions may have on the health care system and larger society.

Beyond Family Conferences

Family conferences have become a standard mechanism for making decisions about subsequent care. As early as 1980, family meetings were proposed as a way to improve patient and family coping and enhance patient care in trauma and critical care units. When first described, family conferences focused primarily on information sharing and emotional support.

Over subsequent decades, most of the literature about family meetings in the intensive care unit (ICU) focused on end-of-life and palliative care decision making. As the focus shifted, outcome measures of family meetings were increasingly judged by their impact on continuance of futile...
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care, length of ICU stay, and cost. In part, this shift was driven by the direction of research since the 1980s, in which palliative care and appropriate use of ICU care have been in the forefront.

Today, communication with families is recognized as an essential component of end-of-life care. In the 1980s, however, little attention was paid to and little research focused on end-of-life care in the ICU or in other care settings. The SUPPORT trial (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) began in 1989, and was a large, multisite study of physician and family communication and decision making. The study tested a 3-fold intervention delivered to families and physicians: study nurses facilitated intensive patient and family counseling, prognostic information was provided to treating physicians, and the wishes of families were elicited and documented.

Although the first phase of the study found substantial shortcomings in communication and decision making, the intervention did not result in any changes. There were no differences in family-physician communication, physician knowledge of patient and family wishes, or use of hospital resources attributable to the SUPPORT intervention. The SUPPORT intervention did not achieve its goals, but it launched a decade of advancement in palliative care, including end-of-life communication in the ICU.

Beginning in 1996 (after the SUPPORT trial) and continuing until 2006, the Robert Wood Johnson Foundation (RWJF) funded the national program, Promoting Excellence in End-of-Life Care. The program’s goal was to substantially improve the care provided to dying people and their families in health care institutions.

In 2002, the Promoting Palliative Care Excellence in Intensive Care initiative was established under the RWJF national program. It sought to find a balance between medically aggressive care and palliative care. Seven end-of-life care domains were identified, and because communication was recognized as a crucial component of improving palliative care, the second domain was “Communication within the Team & Patients/Families.”

Palliative and end-of-life care is one of AACN’s advocacy initiatives. AACN became the repository for the ICU Palliative Care tools developed under the RWJF initiative, and the materials remain available on the AACN Web site. A family meeting guide that was developed in 2006 by Lehigh Valley Hospital and Health Network with RWJF funding is also still available on the AACN Web site and is widely used.

During the past 3 decades, much research has addressed communicating with families in the ICU in the context of end-of-life care. However, much remains to be discovered. Patients who die in the ICU are a minority, currently estimated at about 20%. Most patients survive their ICU experience, but little research has targeted the communication needs of these patients and their families. Patients who survive and their families are at risk of post-traumatic stress disorder. It is not known whether the communication strategies developed for families dealing with palliative care issues are valid in situations in which survival is more likely.

The family conference has been widely incorporated into ICUs. However, the best timing for an initial family conference has not been established, nor has the optimal frequency been determined. Gay and colleagues reported multiple barriers to conducting family conferences in the ICU, such as competing time demands, lack of appropriate space, cultural and language difficulties, and inadequate clinician training in communication skills. Strategies to overcome these and other barriers are needed.

New Approaches Are Needed

New approaches to our interactions with families, beyond formal family conferences, must also be developed and tested. New knowledge about communication and decision making should inform our efforts to improve our interactions with families. As an example, White and colleagues employed a dual-process theory of decision making (the Cognitive Emotional Decision Making framework) to design the Four Supports Intervention. This nurse-led intervention to support surrogate decision makers goes beyond the framework of traditional family conferences to provide emotional support, communication support, decision support, and anticipatory grief support. New approaches should also target the effectiveness of strategies for communication at the bedside. Nurses and families frequently interact at the patient’s bedside, and effective informal communication strategies have not been well studied.
Communication with families does not belong to a single profession. Care is provided by interdisciplinary teams and communication should be interdisciplinary as well. Many research studies have focused on physician communication or nurse communication, but few have examined interventions to improve communication of the team with families. Gay and colleagues state, “Almost universally, it is the bedside nurse who develops the closest relationship with both the ICU patient and the family.”

In their qualitative study of nurse communications in the ICU, Slatore and colleagues identified a theme of a key role for the nurse in serving as a translator or intermediary between physicians and patients/families. However, they further identified that nurses made a distinction between topics that they were and were not willing to discuss with patients and families. Additional research is essential to explore aspects of disciplinary cultures that aid or hinder efforts to support families as an interdisciplinary team.

Conclusion

Critical illness presents unaccustomed challenges to patients and their families. Connection and communication have the potential to improve their experiences. All members of the interdisciplinary team are important in this endeavor. Our focus on end-of-life communication has been important, but it is time to expand our knowledge of family communication and support to encompass the needs of all our patients, regardless of prognosis. Research that tests new models for communication among clinicians, patients, and families is imperative to improve outcomes.

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References


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