

Improving palliative care and communication in the ICU

Provide evidence-based palliative care to critically ill patients and comfort to their families.

By the staff of the National Institute of Nursing Research

This article is the first in a series that will bring the latest developments in nursing science from the National Institute of Nursing Research to practicing nurses.



MORE THAN 500,000 PEOPLE die in American intensive care units (ICUs) every year. And many of the deaths occur after the patient or family makes the difficult decision to withhold or withdraw life-sustaining treatment.

Today, researchers supported by the National Institute of Nursing Research (NINR) are examining how clinicians, patients, and families interact in these stressful circumstances and developing strategies to improve communication about difficult end-of-life (EOL) decisions. (See *What is the NINR?*)

Informing and involving patients

Clinicians know that patients must be involved in treatment discussions and decisions as much as possible. But when patients are critically ill and unstable, their ability to participate can be limited.

Researchers at one hospital observed that clinicians made repeated attempts to inform and involve patients being weaned from prolonged mechanical ventilation. When able, patients provided input for treatment decisions, either verbally or nonverbally. Decisions included whether to continue weaning, place a tracheostomy, and initiate or discontinue other life-sustaining treatments such as dialysis. For each patient, a family member, usually a spouse or an adult child, took part in meetings with ICU clinicians. Often, the family member served as the primary decision maker. Much of the input sought from the patient was to confirm the family member's decision.

With this type of observational study, researchers gain a better understanding of the interactions among clinicians, patients, and families; the ability of patients to make decisions under difficult conditions; and the role of family members in the decision-making process. This knowledge can help clinicians use appropriate communication skills to ensure that treatment decisions reflect the wishes of patients and families.

Communicating with families

Even when a critically ill patient can contribute to discussions, clinicians encourage family members to participate in decision making. To comprehend the situation and the available options, family members need information they can understand and time to ask questions.

One analysis of meetings between families and ICU staff, however, found that clinicians dominate the conversations and miss opportunities to address the family's questions and concerns. In a related study, family members of patients who died in the ICU reported greater satisfaction with communication and decision making than family members of ICU survivors. This surprising result suggests that clinicians make an extra



What is the NINR?

The National Institute of Nursing Research (NINR) is the principal federal agency for funding nursing research. NINR supports basic and clinical research that develops knowledge to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and enhance end-of-life and palliative care. NINR also places a strong emphasis on training the next generation of scientists.

Patricia A. Grady, PhD, RN, FAAN, has been the Director of NINR since 1995. Under her leadership, NINR has extended the reach of nursing research in clinical and community settings. "Through this series of articles, we look forward to working with *American Nurse Today* to get more information into the hands of clinical nurses, helping them use research to improve care at the bedside and the outcomes of their patients," says Dr. Grady.

For more information, please visit the NINR web site at www.ninr.nih.gov.

effort when death is imminent, but pay less attention to the needs of those expected to survive.

In a separate study of EOL patients, researchers explored clinician-family interactions in four ICUs in the same large hospital. All four had informal rules discouraging the nursing staffs from discussing do-not-resuscitate orders with families. In two ICUs, nurse input on family concerns was routinely sought by other clinicians, but not in the other two. Sometimes, family members requested life-support withdrawal in accordance with the patient's advance directive, despite the objections of clinicians. Overall, the study showed variations in clinician-family interactions, depending on the ICU. The study highlighted the need for more research into the types of interactions that affect family and patient satisfaction. (See *The VALUE of skilled communication*.)

Providing palliative and EOL care

Patients in the ICU report a range of symptoms, including pain, anxiety, sleep disturbances, hunger, thirst, and shortness of breath. Many surviving patients experience long-term complications, such as chronic pain and disability. As many as 30% of patients die in the ICU or shortly after discharge. Thus, many ICU patients need palliative care to address symptom management, discharge planning, treatment goals, advance directives, and options to withhold or withdraw life-sustaining treatment.

A survey of ICU nurses who recently cared for a dying patient found that the most common nursing activities included assuring the family of the patient's comfort, explaining medical equipment and procedures, and supporting the family's decisions. Common barriers to good palliative care included unrealistic expectations from the family, staff conflict, and a lack of privacy for family discussions.

Integrating Palliative and Critical Care (IPACC) is an NINR-supported project intended to improve quality in the ICU. The project provides training for the ICU team in palliative and EOL care, methods to improve staff attitudes and overcome barriers to EOL care, and feedback from family satisfaction surveys. As part of this project, a multidisciplinary team developed standardized orders to keep patients comfortable and pain-free when withdrawing a ventilator. A recent clinical trial found that IPACC reduced the ICU length of stay for dying patients and resulted in a more positive assessment of the quality of the dying



The VALUE of skilled communication

To increase family involvement, researchers developed a communication strategy for ICU clinicians based on the mnemonic VALUE:

- **V**alue what the family members say.
- **A**cknowledge their emotions.
- **L**isten.
- **U**nderstand the patient as a person.
- **E**licit questions.

Compared with family members participating in standard conferences, those participating in VALUE-strategy conferences reported less anxiety, depression, and stress at a 3-month follow-up. Scientifically tested interventions such as VALUE may benefit family members who must cope with difficult critical-care decisions.

process. The IPACC research team developed a video that presents the perspectives of critically ill patients, their family members, ICU staff members, and experts on palliative care issues in the ICU. To view it, visit www.ninr.nih.gov.

Enhanced value

A growing body of research demonstrates the dynamic role of nurses in the complex setting of the ICU, especially in the areas of symptom management and communication. Research indicates that clinicians need to spend more time listening to the concerns and answering the questions of patients and their family members and focus more on palliative care and EOL issues. By taking these steps, you can enhance the value of your care for and communication with your patients and their distressed family members. ★

Selected references

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