Experts Propose 18 Quality Measures to Improve Care of the Dying in ICUs

Measuring the quality of end-of-life care in the intensive care unit

**SUMMARY**

Members of the Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup conducted a series of five studies to develop ways to optimize care of patients dying in intensive care units (ICUs).

They also developed a set of measures to assess the processes and outcomes of end-of-life care provided in ICUs.

Convened in 1998 under the auspices of RWJF, the workgroup is a task force of 36 nationally recognized clinicians, educators and investigators in critical care and end-of-life care. The group works to develop a national agenda for research, education and clinical efforts to improve the care of patients dying in ICUs.

**Key Findings**

- As reported in an article in *Critical Care Medicine*, (32(3): 638–643, 2004), the researchers estimate that 22 percent of American deaths in 1999 (540,000 deaths) occurred following an ICU admission.

- As reported in an article in *Critical Care Medicine*, (34(10): 2547–2553, 2006), researchers identified a number of barriers to end-of-life care in ICUs, including:
  - Lack of advance directives.
  - Competing demands for clinician's time.
  - Suboptimal space for family meetings.

- As reported in an article in *Critical Care Medicine*, (31(9): 2255–2262, 2003), researchers identified seven domains in which end-of-life care is provided in the ICU:
  - Patient- and family-centered decision-making.
  - Communication within the team and with patients and families.
— Continuity of care.
— Emotional and practical support for patients and families.
— Symptom management and comfort care.
— Spiritual support for patients and families.
— Emotional and organizational support for ICU clinicians.

  - "Symptom management and comfort care" was the domain of end-of-life care that was integrated most consistently on data entry forms, guidelines and other documents obtained from 15 ICUs.

- As reported in an article in *Critical Care Medicine*, (34(Supplement 11): S404–411, 2006), the research team developed 18 proposed quality measures for end-of-life care provided in the ICU. (See Findings.)

**Funding**

RWJF supported this project through two grants from October 2000 to March 2006 totaling $890,917 to Rhode Island Hospital, the home institution of the workgroup's chair.

**THE PROBLEM**

Despite considerable technological breakthroughs in the provision of intensive care since the 1960s, studies reveal considerable variation in the quality of care patients receive in ICUs:

- One study revealed that overall hospital mortality of patients treated between 1988 and 1990 in intensive care units (ICUs) of 40 U.S. hospitals was up to 40 percent, depending mainly on the severity of illness of patients at admission (Knaus WA, et al, *Annals of Internal Medicine*, 118(10): 753–761, 1993. Available online to subscribers.)

- Research indicates that too many patients dying in the ICU setting continue to suffer pain and other distressing symptoms, and their families and surrogates often report that the quality of communication with clinicians is poor. (Emanuel and Emanuel, *Lancet*, 351(Supplement 2): 21–29, 1998.)

- Evidence indicates that there is wide national variation in end-of-life care in ICUs. For example, one study of ICUs showed that the withdrawal of life support before death ranges from 0 percent to 79 percent, and for compliance with do-not-resuscitate orders, the range was 0 percent to 83 percent (Fowler FJ, et al, *Journal of Pain and Symptom Management*, 17(2): 114–119, February 1999. Available online.)
These perceived inadequacies and wide variations in end-of-life care of critically ill patients have stimulated significant public concern and increasing attention within the community of critical care providers.

Though investigators had previously worked to develop measures of end-of-life care, none of these efforts focused specifically on the care of patients dying in ICUs.

**CONTEXT**

RWJF’s engagement with end-of-life care began with the 1989 funding of SUPPORT, a $28 million, five-year study that looked at nearly 10,000 critically ill patients in five large hospitals, their families and the staff who cared for them.

The first phase of SUPPORT was descriptive, leading the researchers to conclude in the *Journal of the American Medical Association (JAMA)* that "most Americans die in hospitals, often alone and in pain, after days or weeks of futile treatment, with little advance planning, and at high cost to the institution and the family." (*JAMA*, (274)20: 1591–1598, 1995. Available online to subscribers.)

The second phase of SUPPORT was an intervention designed to change that. The approach included intensive counseling for patients and families, frequent meetings with physicians and efforts to make the best possible information about prognosis and preferences available to the care team. In 1994, SUPPORT researchers informed RWJF that the intervention had failed to achieve its intended goals.

SUPPORT taught RWJF that marginal adjustments in approaches to end-of-life care were not going to be enough to overhaul the way in which care is delivered to dying people, and that more ambitious strategies were needed to help change social norms, professional values and social priorities. In an array of programs subsequently developed to improve care at the end of life, RWJF has pursued three strategies:

- Professional education, with projects that include:
  - Five grants to the Medical College of Wisconsin, totaling just under $1.7 million from 1998 to 2005, to train faculty to incorporate end-of-life training into their curriculum for internal medicine, family medicine, neurology and surgery residents. This was part of the college's National Residency End-of-Life Education Project. (See Program Results Report on ID#s 046547, 044826, 041481, 036669, and 032598.)
  - A $380,000 grant from 2001 to 2003 to the American Board of Hospice and Palliative Medicine to implement an accreditation process for fellowship training programs in palliative medicine. (See the Program Results Report on ID# 039835.)
— A 1998 grant to the National Board of Medical Examiners to increase the quantity and quality of end-of-life questions on the medical licensing exam that all U.S. physicians are required to take. (See the Program Results Report on ID# 033887).

• Institutional change, with projects that include:

  — A series of 38 grants totaling more than $23 million, starting in 1999 to the Mount Sinai School of Medicine in New York City to create the Center to Advance Palliative Care with the goal of integrating palliative care into hospitals. RWJF funding runs through June 2011.

• Public engagement, with projects that include:

  — The 1995 Last Acts® campaign, a coalition of more than 800 health and consumer groups that worked to:
    • Improve communication about death and enhance the capacity of consumers to make decisions about their own deaths.
    • Change the culture of health care institutions.
    • Change American culture and attitudes toward death and dying.

  — Starting in 1997, grants to the Center for Practical Bioethics (formerly the Midwest Bioethics Center) at the University of Kansas to operate the Community-State Partnerships to Improve End-of-Life Care national program—see Program Results Report. Under this program, 20 states and the District of Columbia received grants to promote policy changes around end-of-life issues and high-quality palliative care.

  — A 2000 grant to Bill Moyers and the Educational Broadcasting Corp. to produce a four-part television program on the cultural, medical, ethical and spiritual aspects of death and dying in America. (See Program Results Report on ID# 035477.)

The grants described in this report grew out of the Promoting Excellence national program.

See the End-of-Life Care and Palliative Care sections of RWJF's website for more information on RWJF's work in these areas.

THE PROJECT

Members of the Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup conducted a series of five studies to develop ways to optimize care of dying patients in intensive care units (ICUs).

They also developed a set of measures to assess the processes and outcomes of end-of-life care provided in ICUs.
The workgroup is an interdisciplinary task force of 36 nationally and internationally recognized clinicians, educators and investigators in critical care and end-of-life care. RWJF convened the workgroup as a companion activity to RWJF’s national program, *Promoting Excellence in End-of-Life Care* (for more information see [*Program Results Report*](#)).

The studies focused on:

- The epidemiology of deaths in ICUs in the United States.
- A survey of ICU directors on end-of-life care in ICUs.
- Identifying the domains of end-of-life care in the ICU.
- A content analysis of end-of-life care documents in ICUs.
- Developing quality measures for palliative care in the critically ill.

The workgroup viewed this project as an essential step in the process of standardizing, and eventually, benchmarking, optimal end-of-life care for dying patients and their families in the ICU setting.

**The Epidemiology of Deaths in ICUs in the United States**

The research team examined hospital discharge data from 1999 for six states and the Centers for Disease Control and Prevention’s National Death Index. Using these data, they calculated age-specific rates of hospitalization with and without ICU use at the end-of-life. They then generated national estimates of end-of-life hospital and ICU use.

The six states—used because they comprise 22 percent of the U.S. population and have high quality hospital discharge data—included:

- Florida
- Massachusetts
- New Jersey
- New York
- Virginia
- Washington

**Survey of ICU Directors on End-of-Life Care in ICUs**

Researchers developed and fielded a 32-question, self-administered survey of end-of-life ICU practices, barriers to optimal care and strategies for improvement. The goal was to understand the perceptions of ICU directors regarding end-of-life care, and barriers and solutions to best practice.
Researchers mailed the survey to a random, nationally representative sample of nursing and medical directors of 600 adult ICUs in the United States. They received 499 responses, representing more than 400 (70%) of the ICU sample.

**Identifying Domains of End-of-Life Care in the ICU**

The research team sought to identify key domains end-of-life care provided in ICUs. They then developed quality performance indicators within each of these domains of care. The goal was to address the wide variation in end-of-life care in ICUs nationally.

The research team:

- Conducted a review of more than 100 sources from the medical and nursing literature.
- Consulted with members of the RWJF Critical Care End-of-Life Peer Workgroup and other experts, using a consensus process to identify domains of end-of-life care provided in the ICU.
- Developed quality performance indicators within each domain. Clinicians could use these indicators to determine the level of quality achieved in end-of-life care in the ICU.
- Solicited input from nurse-physician teams from 15 ICUs (clinical practice sites of members of the Critical Care End-of-Life Peer Workgroup), asking them to suggest specific clinician and organizational behaviors and interventions that clinicians can use to address the proposed quality indicators.
- Reviewed the suggestions and comments and categorized innovative ones within the list of quality indicators.

**Content Analysis of End-of-Life Care Documents in ICUs**

The research team analyzed data entry forms, guidelines and other materials used for documentation obtained from 15 adult ICUs in the United States (medical, surgical and mixed). The goal was to determine the extent to which the documents focus on end-of-life care, and to see how they might be improved.

The team performed content analyses on the documents, determining the extent to which they supported six end-of-life care domains. The domains were:

- Patient- and family-centered decision making.
- Communication within the team and patients and families.
- Continuity of care.
- Emotional and practical support for patients and families.
• Symptom management and comfort care.

• Spiritual support for patients and families.

(A seventh domain—emotional and organizational support for ICU clinicians—had not yet been identified.)

**Developing Quality Measures for Palliative Care in the Critically Ill**

The research team worked to develop a preliminary set of quality measures to assess palliative care in the critically ill.

The team identified and refined a set of candidate quality measures through the following steps:

• Reviewed previous literature in the field.

• Supplemented the evidence base with recently published systematic reviews and consensus statements.

• Identified and adapted existing indicators and measures, including:
  — A palliative care quality measurement tool developed and tested by the national Transformation of the ICU performance improvement project of the Voluntary Hospital Association. (Abstract available and article available for purchase online.)
  — A government-sponsored systematic review performed by RAND Health to identify palliative care quality measures for cancer care. (Available online.)

• Conducted an informal consensus process with an international panel of experts in palliative and end-of-life care in critical care settings to select the quality measures. The panel included:
  — Researchers.
  — Ethicists.
  — Lawyers.
  — Administrators.
  — Clinicians spanning the disciplines of surgery, medicine, nursing, critical care, palliative care, pediatrics and family practice.
**FINDINGS**

**The Epidemiology of Deaths in ICUs in the United States**

As reported in an article in *Critical Care Medicine*, (32(3): 638–643, 2004):

- **Nearly one-quarter (22.4%) of the 552,157 deaths in the six states in 1999 occurred in ICUs.** Deaths in ICUs represented 59 percent of all hospital deaths. Based on these figures, the researchers estimate that some 540,000 people died in the United States in 1999 following an ICU admission.

- **ICU use at the end of life varied by age:**
  - ICU use at the end-of-life was highest for infants (43%).
  - ICU use at the end-of-life ranged from 18 percent to 26 percent across older children and adults.
  - ICU use at the end-of-life fell to 14 percent for those older than 85 years.

- **Average length of stay and costs were 12.9 days and $24,541 for terminal patients hospitalized in ICUs, and 8.9 days and $8,548 for terminal patients hospitalized in other hospital units.**

**Survey of ICU Directors on End-of-Life Care in ICUs**

As reported in an article in *Critical Care Medicine*, (34(10): 2547–2553, 2006), ICU directors ranked the following barriers to end-of-life care in ICUs from "huge" (1) to "not at all" (5):

- **Patient and family factors, including:**
  - Unrealistic expectations (2.5).
  - Patient's inability to participate in discussions (2.6).
  - Lack of advance directives (2.9).

- **Clinical factors, including:**
  - Insufficient training in communication (2.9).
  - Competing demands for clinician's time (3.0).

- **Institutional and ICU factors, including:**
  - Suboptimal space for family meetings (3.5).
  - Lack of palliative service (3.4).
Among 14 strategies considered by more than 80 percent of respondents to be helpful in end-of-life care, few were widely available, but included:

- Trainee role modeling by experienced clinicians.
- Clinician training in end-of-life communication.
- Regular meetings of senior ICU clinicians with families.
- Bereavement programs.
- End-of-life care quality monitoring.

### Identifying Domains of End-of-Life Care in the ICU

As reported in an article in *Critical Care Medicine*, (31(9): 2255–2262, 2003):

- Researchers identified seven domains of end-of-life care in the ICU:
  - Patient- and family-centered decision making.
  - Communication within the team and with patients and families.
  - Continuity of care.
  - Emotional and practical support for patients and families.
  - Symptom management and comfort care.
  - Spiritual support for patients and families.
  - Emotional and organizational support for ICU clinicians.

- Within the seven domains, researchers identified 53 quality indicators that clinicians can use to determine the level of quality achieved in end-of-life care in the ICU. In addition they identified 100 interventions and/or practices corresponding with the indicators. A complete list of quality indicators and associated interventions and behaviors is available online.

### Content Analysis of End-of-Life Care Documents in ICUs


- "Symptom management and comfort care," particularly in the area of pain assessment and management, was the domain of end-of-life care integrated most consistently on forms and other materials obtained from the 15 ICUs.

- Five other domains examined were not well represented on ICU forms and documentation.
  - Patient- and family-centered decision making.
— Communication within the team and with patients and families.
— Continuity of care.
— Emotional and practical support for patients and families.
— Spiritual support for patients and families.

● None of the 15 ICUs supplied a comprehensive end-of-life policy or critical pathway that outlined an overall, interdisciplinary, sequenced approach for the care of dying patients and their families.

● Across the 15 ICUs, there were opportunities to make end-of-life care-related materials more capable of triggering and documenting specific end-of-life care clinical practices. For example:
  — The majority of ICUs had policies regarding forgoing life-sustaining treatments, but only half of them had protocols or standing orders to cue and guide clinicians in the care of patients from whom mechanical ventilation is being withdrawn.

**Developing Quality Measures for Palliative Care in the Critically Ill**

As reported in an article in *Critical Care Medicine*, (34(Supplement 11): S404–411, 2006):

● The research team developed 18 proposed quality measures, each categorized within one of the seven domains of quality palliative care for the critically ill:

  **Patient and Family-Centered Decision Making**
  — Assessment of the patient's decisional capacity.
  — Documentation of a surrogate decision maker within 24 hours of admission.
  — Documentation of the presence and, if present, contents of advance directives.
  — Documentation of the goals of care. Communication within the Team and With Patients and Families
  — Documentation of timely physician communication with the family.
  — Documentation of a timely interdisciplinary clinician-family conference.

  **Continuity of Care**
  — Transmission of key information with transfer of the patient out of the ICU.
  — Policy for continuity of nursing services.

  **Emotional and Practical Support for Patients and Families**
  — Open visitation policy for family members.
— Documentation that psychosocial support has been offered.

**Symptom Management and Comfort Care**
— Documentation of pain assessment.
— Documentation of pain management.
— Documentation of respiratory distress assessment.
— Documentation of respiratory distress management.
— Protocol for analgesia/sedation in terminal withdrawal of mechanical ventilation.
— Appropriate medications available during withdrawal of mechanical ventilation.

**Spiritual Support for Patients and Families**
— Documentation that spiritual support was offered.

**Emotional and Organizational Support for ICU Clinicians**
— Opportunity to review experience of caring for dying patients by ICU clinicians.

**AFTERWARD**
Members of the Critical Care End-of-Life Peer Workgroup continue to meet informally. They are developing tools, based on the above measures, which ICU doctors and nurses can use to assess the processes and outcomes of end-of-life care provided in their units.

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