A Tale of two specialties – Merging Palliative care into Critical Care

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ICU – Journal presentation
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Introduction

- Death in the Intensive Care Unit (ICU) is often inevitable
- ~ 20% (ranged from 6 to 41%) of patients die before discharge

Unsuccessful intensive care

Maximized medical support with advanced technology

Maximizing comfort

- Discussion of medical futility of treatment and end-of-life issue is given less attention
Introduction

- Family conferences, spiritual care, social worker interview were not well-recorded in the ICU medical record
- Decisions to withhold/withdraw treatments are variably documented and largely subtle that are difficult or impossible to capture in chart review
- One would have to agree on which patients needed these interventions before one could agree that they had been withheld
- Few guidelines/practices for terminal weaning of ventilator
Introduction

The ICU may not be an ideal place to die:

- Patients are isolated from their families
- Neurologically depressed to make communication NOT feasible
- Uncertainty about medical directives
- Problem associated with assessment of pain and other symptom control
- Care by different specialty teams
Introduction

- What are the barriers to end-of-life care in ICU?
- What are the attitudes of health care staff?
- What is quality end-of-life care in ICU?
- How to measure success of intervention?
- Any role of palliative care services in ICU?
What are the barriers to end-of-life care in ICU?
Barriers to End-of-life care in ICU

1. Difficulty in identifying who should receive EOL care in ICU
   - Patients with a predicted length of stay longer than 5 days, predicted mortality > 25% as estimated by the attending physician, or change in functional status that was potentially irreversible


2. Prognostic uncertainty

Barriers to End-of-life care in ICU

3. < 5% patients are communicable for decision-making
   - ? patients’ preferences for resuscitation (know only moderately better than chance)
   - In one study, 78% of patients stated that if their previous preferences differed from a decision made by their family and physician

4. Poor decision making arises from conflict and inadequate information between physician-staff-family triad

J. Randall Curtis, Sarah E. Shannon.
Transcending the silos: toward an interdisciplinary approach to end-of-life care in the ICU.
Barriers to End-of-life care in ICU

- Mean duration of a family meeting was 10 mins
- The families reported not understanding the diagnosis, prognosis or care plan ~ 54%
- Clinicians spoke most of the time ~ 71%
- No association between the duration of the conference and family satisfaction

Critical Care Medicine 2006; 34: S306-S308.
Barriers to End-of-life care in ICU

- Semi-structured interviews on a sample of 21 nurses from two community hospitals:
  - Nurses stated that it was important for the physician to give the patient and family member a clear, accurate and realistic prognosis
  - Nurses also thought that physicians were much more optimistic than the nurses, or presented things to the family with more optimism

Kathleen A. Puntillo, Jennifer L. McAdam.
Communication between physicians and nurses as a target for improving end-of-life care in the intensive care unit: Challenges and opportunities for moving forward.
Critical Care Medicine 2006; 34(11): S332-S340
Barriers to End-of-life care in ICU

5. Insufficient training of ICU physicians in palliative medicine

6. Inflated expectations for critical care therapies (which are shared by many clinicians, patients and families)
   • “Death-denying” society
   • Lack of education or knowledge about critical care

Barriers to End-of-life care in ICU

Table 2. Barriers to optimal end-of-life care

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>No. (%) Rating Large or Huge</th>
<th>Mean (sd) Rating</th>
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<tbody>
<tr>
<td><strong>Patient/family barriers</strong></td>
<td></td>
<td></td>
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<tr>
<td>Unrealistic patient and/or family expectations about prognosis or effectiveness of ICU treatment</td>
<td>272 (48.7)</td>
<td>2.5 (1.0)</td>
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<tr>
<td>Inability of many patients to participate in treatment discussions</td>
<td>259 (46.6)</td>
<td>2.7 (0.9)</td>
</tr>
<tr>
<td>Lack of advance directives</td>
<td>191 (34.2)</td>
<td>3.0 (1.0)</td>
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<tr>
<td>Disagreements within families about care goals</td>
<td>184 (33.0)</td>
<td>2.9 (1.0)</td>
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<tr>
<td>Absence of a surrogate decision maker for patients lacking decisional capacity</td>
<td>136 (24.3)</td>
<td>3.1 (0.9)</td>
</tr>
<tr>
<td>Disagreements between patients/families and the ICU team about care goals</td>
<td>91 (16.3)</td>
<td>3.4 (0.9)</td>
</tr>
<tr>
<td>Refusals by patients/families to forgo life-sustaining treatments for religious reasons</td>
<td>49 (8.8)</td>
<td>3.8 (0.8)</td>
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<tr>
<td><strong>Institutional/ICU factors</strong></td>
<td></td>
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<tr>
<td>Suboptimal space for meeting with families of ICU patients</td>
<td>142 (25.3)</td>
<td>3.5 (1.2)</td>
</tr>
<tr>
<td>Lack of a palliative care service to which a dying patient can be transferred</td>
<td>140 (25.0)</td>
<td>3.4 (1.2)</td>
</tr>
</tbody>
</table>

A survey involving nationally representative sample of nursing and physician directors in 600 adult ICUs in the United States

Judith E. Nelson, Derek C. Angus, Lisa A. Weissfeld.
End-of-life care for the critically ill: A national intensive care unit survey.
Critical Care Medicine 2006; 34:102547-2553.
Barriers to End-of-life care in ICU

7. Distrust of the healthcare system
   - Fear that palliative care will provide lower quality care

8. Inadequate financing and insurance coverage for palliative care

9. Lack of diversity in hospice and palliative care teams to the cultural values of diverse communities
What are the attitudes of health care staff?
With regard to the practice of withholding and withdrawing treatment...

- Studies reported **wide variations** in individual ICUs and groups of ICUs in Spain, Europe, and the United States.

- Withdrawal of all active treatment was widespread in ICUs in the United Kingdom. However, there was considerable variation by unit, even after accounting for patient factors and differences in size and type of ICU.

Hannah Wunsch, David A. Harrison, Sheila Harvey, et al.  
End-of-life decisions: a cohort study of the withdrawal of all active treatment in intensive care units in the United Kingdom.  

End-of-Life Practices in European Intensive Care Unit.  
Factors independently associated with the decision to withdraw active treatment

- Older age
- Pre-existing severe medical conditions
- Emergency surgery or medical admission
- Cardiopulmonary resuscitation in the 24 h prior to admission
- Ventilation or sedation/paralysis in the first 24 h after admission
Withholding or placing an upper limit on treatment and partial withdrawal of treatment are common practice in ICUs.

•The withholding and withdrawal of therapy from patients with no chance of recovery to a meaningful life is common in Hong Kong (99% and 89%, respectively).

When the family wanted aggressive life-support despite recommendations to limit therapy, 62% of the respondents would still withhold therapy while only 9% would withdraw therapy.
What is quality end-of-life care in ICU?
Defining the Scope of Palliative and End-of-Life Care

No consensus definition of the end of life exists in the literature to guide investigation of quality

(In ICU setting, the formulation of a definition for the end-of-life period will depend on the aspect of quality end-of-life care grounded in discussions of goals of care, to attempt to maintain a patient–family perspective)

Defining the Scope of Palliative and End-of-Life Care

Four schemas have been applied in specifying the end-of-life period:
1) Active dying
2) Acceptance of treatment limitations
3) Severity of illness
4) Poor prognosis

Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments showed that, even very near to death, much uncertainty exists in prognostication; median prognoses within the last week of life were often 50% to survive 6 months.

Defining the Scope of Palliative and End-of-Life Care

WHO defines palliative care as “an approach that improves the quality of life . . . of patients and their families . . . [for] problems associated with life-threatening illness . . . through the prevention and relief of suffering by . . . early identification, . . . assessment, and . . . treatment of pain and other problems, physical, psychosocial and spiritual”
Examining the quality of end-of-life care in the ICU

- Robert Wood Johnson Foundation (RWJF) Critical Care End-of-life Peer Workgroup
- In-depth literature review and consensus process to identify the key EOL care and related quality indicators, a number of quality-of-care domains were proposed:

1) Patient- and family-centered decision making
2) Communication with patients and family
3) Continuity of care
4) Emotional and practical support for patients and family members
5) Symptom management and comfort care
6) Spiritual support
7) Emotional and organizational support for ICU clinicians

Ellen B. Clarke, J. Randall Curtis, John M. Luce, et al.
Quality indicators for end-of-life care in the intensive care unit.
Critical Care Medicine 2003; 31: 2255-2262.
Table 2. Quality indicators for end-of-life care (EOLC) (bulleted) within each of the seven EOLC domains (numbered) in the intensive care unit (ICU)

1. Patient and family-centered decision making
   • Recognize the patient and family as the unit of care
   • Assess the patient’s and family’s decision-making style and preferences
   • Address conflicts in decision making within the family
   • Assess, together with appropriate clinical consultants, the patient’s capacity to participate in decision making about treatment and document assessment
   • Initiate advance care planning with the patient and family
   • Clarify and document the status of the patient’s advance directive
   • Identify the healthcare proxy or surrogate decision maker
   • Clarify and document resuscitation orders
   • Assist patients and families that decision making by the healthcare team will incorporate their preferences
   • Follow ethical and legal guidelines for patients who lack both capacity and a surrogate decision maker
   • Establish and document clear, realistic, and appropriate goals of care in consultation with the patient and family
   • Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient’s condition changes
   • Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected

2. Communication within the team and with patients and families
   • Meet as interdisciplinary team to discuss the patient’s condition, clarify goals of treatment, and identify the patient’s and family’s needs and preferences
   • Address conflicts among the clinical team before meeting with the patient and/or family
   • Utilize expert clinical, ethical, and spiritual consultants when appropriate
   • Recognize the adaptations in communication strategy required for patients and families according to the chronic vs. acute nature of illness, cultural and spiritual differences, and other influences
   • Meet with the patient and/or family on a regular basis to review patient’s status and to answer questions
   • Communicate all information to the patient and family, including distressing news, in a clear, sensitive, unhurried manner, and in an appropriate setting
   • Clarify the patient’s and family’s understanding of the patients’ condition and goals of care at the beginning and end of each meeting
   • Designate primary clinical liaison(s) who will communicate with the family daily
   • Identify a family member who will serve as the contact person for the family
   • Prepare the patient and family for the dying process

3. Continuity of care
   • Maximize continuity of care across clinicians, consultants, and settings
   • Orient new clinicians regarding the patient and family status
   • Prepare the patient and/or family for a change of clinician(s) and introduce new clinicians

4. Emotional and practical support for patients and families
   • Elicit and attend to the needs of the dying person and his/her family
   • Distribute written material (booklet) for families that includes orientation to the ICU environment and open visitation guidelines, logistical information (nearby hotels, banks, restaurants, directions), listings of financial consultation services, and bereavement programs and resources
   • Facilitate strengthening of patient-family relationships and communication
   • Maximize privacy for the patient and family
   • Value and support the patient’s and family’s cultural traditions
   • Arrange for social support for patients without family or friends
   • Distribute written material (booklet) containing essential logistical information and listings of financial consultation services and bereavement support programs/resources
   • Support the family through the patient’s death and their bereavement
The Workgroup proposed 53 “quality indicators” within those domains and identified 100 “examples of clinician and organizational behaviors that could address the end-of-life care quality indicators in the intensive care unit setting”
Interventions to improve quality of End-of-life care in the ICU

- Value end-of-life care and routinely include it on rounds and in notes
- Schedule formal family conferences with specific talking points early in ICU course
- Use protocols for withholding and withdrawing life-sustaining treatments
- Provide nurses with documentation standards for withholding and withdrawing life-sustaining treatments
- Communicate decisions clearly about which treatments should be withheld
- Address exaggerated concerns over legal and ethical barriers to providing care to dying patients
- Convene multi-disciplinary rounds to review deaths that cover the medical and emotional aspects of caring for dying patients
- Liberalize family visiting hours
- Provide educational pamphlets for families of critically ill patients
How to measure success of intervention?
Measure success of intervention

A number of outcome measures used to evaluate end-of-life care in the ICU

1) ICU length of stay and intensity of care
2) Patients’ symptoms
3) Family members’ symptoms associated with end-of-life care for the patient
4) Families’ and clinicians’ ratings of the quality of satisfaction with care

Measure success of intervention

1. **ICU length of stay and intensity of care**
   - Examining the length of stay for patients who die either with or without an intervention
   - This outcome assumes that prolongation of dying is a marker of poor-quality care

2. **Surrogates’ assessments** substituted for patients’ assessments may not accurately reflect the patient’s experience
   - Some scales employed: NRS/ Short form of the McGill Pain Questionnaire/ Edmonton Symptom Assessment Scale

Measure success of intervention

3. **Family members’ symptoms** associated with end-of-life care for the patient

- High levels of anxiety and depression among family members associated with aspects of ICU care
- Azoulay et al. in France and found that 33% of family members had significant symptoms of PTSD at 3 months
- No studies of complicated grief among

Measure success of intervention

4. Families’ and clinicians’ ratings of the quality of satisfaction with care

- Few instruments have been adapted or have been evaluated for psychometric performance in ICU
- 90% of dying ICU patients have altered cognition, most evaluations will need to involve proxy reports and validity challenges

Examples consist of multiple domains:
- Palliative Care Outcome Scale
- Quality of Dying and Death
- Quality of End-of-Life Care and Satisfaction with Treatment
- Quality of Life at End of Life
- Family Satisfaction in the Intensive Care Unit
- Toolkit After-Death Bereaved Family Member Interview

Measure success of intervention

4. Families’ and clinicians’ ratings of the quality of satisfaction with care

Measures of the quality of end-of-life care in the ICU

- Family Satisfaction in the ICU questionnaire (developed and validated by Heyland et al. 24 items using Likert scales, 14 describe family satisfaction with care and ten describe family satisfaction with decision making)

- Quality of Patients’ Dying Experiences (QODD) questionnaire
  - Levy et al. reported that nurses and resident physicians gave more negative ratings than family members
  - Hodde et al. ICU nurse-assessed QODD demonstrated significantly higher quality of dying among patients who did not receive cardiopulmonary resuscitation in the last 8 hrs of life and for patients who had someone present at the time of their death
  - Responsiveness to interventions is not yet known

Any role of palliative care services in ICU?
Integration of palliative care team into an intensive care unit

Preliminary report of the integration of a palliative care team into an intensive care unit

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Vladimir Kvetan  Critical Care Medicine, Department of Anesthesiology and Clinical Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, New York, NY, USA
• Convenience sample of 157 consecutive patients served by a palliative care team which from August 2005 until August 2007
• Interviews were conducted with a sample of family members
• Education on the death process in 85% of families

• Following consultation with the Palliative Care Service, patients were:
  Disconnected from mechanical ventilators – 29%
  Discontinued inotropic support - 15.9%
  Stopped artificial nutrition - 15.3%
  Stopped dialysis – 6.4%
  Discontinued artificial hydration - 2.5%
• Increase in the rate of the formalization of advance directives
• 83.4% of patients had ‘do not resuscitate’ orders after the intervention

A separate case–control study in 22 persons who died with and 43 who died without a palliative care consultation at the intervention campus ICU

Median survival times from admission were not significantly different when stratified by palliative care consultation status: 12 days for the control group (95% CI 8–18) and 13.5 days for the intervention group (95% CI 8–20).
• Median charges for the use of opioid medications were higher (p=0.01) for the intervention group but lower for use of laboratory (p=0.004) and radiology tests (p=0.027)

• Integration of palliative care experts into the operation of critical care units is of benefit to patients, families and critical care clinicians

Preliminary report of the integration of a palliative care team into an intensive care unit. Sean O’Mahony et al. Palliative Medicine 2010
Any role of palliative care services in ICU?

- ICU-focused palliative care consultation service at Detroit Receiving Hospital (USA) since 1986
  - Comparison of patient with global cerebral ischemia after cardiac arrest or multiple organ system failure and a matched historical control group
  - Identification of advance directive or preferences, if any; communication of prognosis and treatment options with patients or their surrogates; and implementation of palliative care strategies
  - Decreased use of non-beneficial interventions, lag time between identification of poor prognosis and palliative care, reductions in hospital length of stay and hospital charges, with no difference in patient mortality

Margaret L. Campbell. Palliative care consultation in the intensive care unit
Critical Care Med 2006
Table 2. Key interventions

1. Collaborate with intensive care unit leaders—nursing and physicians as partners in the "top-down" direction of the project
2. Palliative care nurse champions as "bottom-up advocates"
3. Staff education, especially around:
   - Communication skills
   - Goals of care and shared decision making
   - Psychosocial assessment and management
   - Cultural sensitivity
   - Symptom management
   - Existential/spiritual suffering
4. Palliative care specialist on rounds for modeling and teaching key behaviors:
   - Interdisciplinary teamwork
   - Patient- and family-centered care
   - Concern for psychosocial distress
   - Attention to physical comfort
   - Review of goals of care
   - Family communication
5. Promote family meetings through teaching, role play, modeling, coaching, and providing and encouraging feedback
6. Open visiting hours
7. "Get to know me" poster to help deliver patient from anonymity
8. Staff support
Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine

Robert D. Truog, MD, MA; Margaret L. Campbell, PhD, RN, FAAN; J. Randall Curtiss, MD, MPH; Curtis E. Haas, PharmD, FCCP; John M. Luce, MD; Gordon D. Rubenfeld, MD, MSc; Cynda Hylton Rushton, PhD, RN, FAAN; David C. Kaufman, MD

*Background:* These recommendations have been developed to improve the care of intensive care unit (ICU) patients during the dying process. The recommendations build on those published in 2003 and highlight recent developments in the field from a U.S. perspective. They do not use an evidence grading system because most of the recommendations are based on ethical and legal principles that are not derived from empirically based evidence.

*Principal Findings:* Family-centered care, which emphasizes the importance of the social structure within which patients are embedded, has emerged as a comprehensive ideal for managing end-of-life care in the ICU. ICU clinicians should be competent in all aspects of this care, including the practical and ethical aspects of withdrawing different modalities of life-sustaining treatment and the use of sedatives, analgesics, and nonpharmacologic approaches to easing the suffering of the dying process. Several key ethical concepts play a foundational role in guiding end-of-life care, including the distinctions between withholding and withdrawing treatments, between actions of killing and allowing to die, and between consequences that are intended vs. those that are merely foreseen (the doctrine of double effect). Improved communication with the family has been shown to improve patient care and family outcomes. Other knowledge unique to end-of-life care includes principles for notifying families of a patient’s death and compassionate approaches to discussing options for organ donation. End-of-life care continues even after the death of the patient, and ICUs should consider developing comprehensive bereavement programs to support both families and the needs of the clinical staff. Finally, a comprehensive agenda for improving end-of-life care in the ICU has been developed to guide research, quality improvement efforts, and educational curricula.

*Conclusions:* End-of-life care is emerging as a comprehensive area of expertise in the ICU and demands the same high level of knowledge and competence as all other areas of ICU practice. (Crit Care Med 2008; 36:953–963)

**Key Words:** ethics; intensive care unit; end-of-life; palliative care; decision making; quality improvement
Table 2. Strategies for improving end-of-life communication in the intensive care unit (ICU)

1. Communication skills training for clinicians
2. ICU family conference early in ICU course (118)

*Evidence-based recommendations for conducting family conference:*
   - Find a private location (21).
   - Increase proportion of time spent listening to family (26).
   - Use “VALUE” mnemonic during family conferences (22).
     - Value statements made by family members.
     - Acknowledge emotions.
     - Listen to family members.
     - Understand who the patient is as a person.
     - Elicit questions from family members.
   - Identify commonly missed opportunities (25, 149).
     - Listen and respond to family members.
     - Acknowledge and address family emotions.
     - Explore and focus on patient values and treatment preferences.
     - Affirm nonabandonment of patient and family.
     - Assure family that the patient will not suffer (24).
     - Provide explicit support for decisions made by the family (24).

*Additional expert opinion recommendations for conducting family conference:*
   - Advance planning for the discussion among the clinical team
     - Identify family and clinician participants who should be involved.
     - Focus on the goals and values of the patient.
     - Use an open, flexible process.
     - Anticipate possible issues and outcomes of the discussion.
     - Give families support and time.
3. Interdisciplinary team rounds
4. Availability of palliative care and/or ethics consultation (115, 116)
5. Development of a supportive ICU culture for ethical practice and communication (108)
Conclusion

- Palliative and end-of-life care in the ICU is an appropriate and underdeveloped area
- With regard to the practice of withholding and withdrawing treatment, variations in individual ICUs
- Preliminary evidence suggest that integration of palliative care into the operation of critical care units may be associated with
  - Improved quality
  - Higher rates of formalization of advance directives and utilization of hospice
  - Lower use of certain non-beneficial life-prolonging treatments
Conclusion

• There is increasing consensus within the field of critical care on shared decision making and the importance of caring for patients’ families

• Communication is consistently identified as the most important and least accomplished factor in quality of care
Conclusion

- Increasing interest in identifying and testing patient- and family-centered outcomes of end-of-life care in the ICU

- Further research is needed to develop a valid and responsive measures of the effectiveness of interventions designed to improve end-of-life care in the ICU
Reference

Reference

The End

Thank you