

Defining Standards for ICU Palliative Care: A Brief Review from The IPAL-ICU Project

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Introduction. In this monograph, we review domains, frameworks, clinical recommendations and measures that have been developed with the specific goal of improving palliative care in the critical care setting. The National Consensus Project for Quality Palliative Care and the National Quality Forum have established standards for high-quality palliative care across a spectrum of clinical settings in which seriously ill patients and their families receive treatment.^{1,2} While many of these standards are applicable and clinically sensible for ICU palliative care, they do not specifically address the ICU.

The approaches we discuss below cover a broad range of clinical activities, with substantial overlap in certain areas that have been separately addressed by multiple professional groups. Most have not been made operational as standards or specified for clinical implementation, although they can serve to guide identification of standards for an ICU palliative care initiative. To succeed in such an initiative, it will be important to select a limited group of standards that are relevant, feasible and practical for use in a particular critical care setting, and to specify them for reliable adherence and assessment of performance. Our brief overview of potential standards suggested by the work of various “stakeholders” is intended to help frame such an effort. As an example, we describe a set of adult ICU palliative care processes measured in the Voluntary Hospital Association’s “Care and Communication Bundle,”³ which has been posted by the National Quality Measures Clearinghouse of the Agency for Healthcare Research and Quality.⁴ We conclude with a summary of key points about implementing standards as part of an ICU palliative care initiative.

Key Domains of ICU Palliative Care. Domains of ICU palliative care have been identified by critical care professionals and by patients and their families.

Table 1. Domains of ICU Palliative Care Quality as Defined by Critical Care/Palliative Care Professionals and by Adult ICU Patients/Families	
A. Professionals’ Definition (Experts in critical care and palliative care)⁵	B. Patients’ and Families’ Definition (Recovered patients with ≥ 5-day ICU stay, families of survivors and nonsurvivors)⁶
Symptom management and comfort care	Clinical care of the patient: -Maintaining comfort, dignity, personhood, privacy
Communication within team and with patients/families	Communication by clinicians: -Timely, ongoing, clear, complete, compassionate -Addressing condition, prognosis, treatment
Patient- and family-centered decision making	Patient-focused medical decision making: -Aligned with patient values, care goals, treatment preferences
Emotional and practical support for patients and families	Care of the family: -Open access and proximity to patients -Interdisciplinary support in the ICU -Bereavement care for families of patients who died
Spiritual support for patients and families	
Continuity of care	
Emotional and organizational support for ICU clinicians	

Domains Defined by Critical Care Professionals. In 2002–3, the Critical Care Peer Workgroup of the Robert Wood Johnson Foundation’s Promoting Excellence in End-of-Life Care project, an interdisciplinary task force of expert clinicians, educators and investigators in critical care and palliative care, used literature review and expert consensus to identify seven key domains of palliative care quality.⁵ These domains are: 1) symptom management and comfort care; 2) communication within the team and with patients and families; 3) patient- and family-centered decision making; 4) emotional and practical support for patients and families; 5) spiritual support for patients and families; 6) continuity of care; and 7) emotional and organizational support for ICU clinicians (**Table 1A**, above).

Within these seven domains, the Workgroup proposed more than 50 potential quality indicators and more than 100 clinical behaviors and organizational interventions that could illustrate application of the indicators in the ICU. For example, within “continuity of care,” a key domain, indicators included: “Prepare the patient and/or family for a change of clinician[s] and introduce new clinicians.” For the suggested indicator “Value and support the patient’s and family’s cultural traditions,” illustrative behaviors included “Provide staff with an overview of various cultures’ significant rituals around death and dying” and “Allow for cultural differences in dying rituals and body care after death whenever possible.” **Table 2** below shows selected indicators and examples of performance on indicators within the Workgroup’s “symptom management and comfort care” domain.

Table 2. Selected Proposed Quality Indicators and Illustrative Clinician/Organizational Behaviors Within the “Symptom Management and Comfort Care” Domain by the Critical Care Peer Workgroup of the Robert Wood Johnson Foundation’s Promoting Excellence in End-of-Life Care Project⁵	
Quality Indicators (examples selected from > 50)*	Examples of Performance (selected from > 100)*
<i>Institute and use uniform quantitative symptom assessment scales appropriate for communicative and noncommunicative patients on a routine basis.</i>	Symptom assessment scales and/or guidelines available at bedside** as resources
	Demonstration of methods by which Joint Commission’s pain standards are met
	Bedside** flow sheet includes areas to document the assessment of other symptoms (anxiety, thirst, dyspnea, agitation, confusion and delirium)
	Documentation that pain and symptom assessment is part of every critical care staff nurse and resident orientation program
<i>Standardize and follow best clinical practices for symptom management.</i>	Written and referenced ICU protocols for multiple symptom assessment and management procedures
	Referenced analgesic/benzodiazepine equivalency charts available at each bedside**

*Across the seven domains of ICU palliative care quality, the Critical Care Peer Workgroup listed a total of 53 quality indicators. As examples, the left-hand column of our table sets forth two among ten indicators within the “symptom management and comfort care” domain. The Workgroup identified more than 100 examples of clinician and organizational performance on the 53 suggested indicators, but included only a small number of these in the published report (which provides an online source for additional examples). In the right-hand column of this table, we provide examples from the published report for the indicators we included at left in our table.

** The Workgroup did not refer explicitly to use of resources in electronic medical records, but, increasingly, those might be used for these “bedside” purposes.

of recovered ICU patients, families of patients who survived intensive care and families of patients who died in the ICU.⁶ Patients and families in this study had experienced care in different types of ICUs, hospitals and local environments across the country. They represented diverse ethnic and religious backgrounds. Yet they expressed strong agreement about four main domains of high-quality ICU palliative care: 1) patient care maintaining comfort, dignity and personhood; 2) timely, clear and compassionate communication by clinicians; 3) clinical decision making focused on patients' preferences, goals and values; and 4) interdisciplinary support of families during the critical illness and, for families of patients who died in the ICU, in the bereavement period (**Table 1B**). These domains are similar in important respects to those identified by professionals in the Critical Care Peer Workgroup (**Table 1A**), by other pulmonary/critical care professionals,^{7, 8} and by professionals in other fields addressing palliative care.¹ They also overlap with views expressed by patients or families in clinical settings other than the ICU.^{9, 10}

Bereaved Parents Identify Domains of Pediatric ICU Palliative Care. A study conducted at three pediatric ICUs (PICUs) in a northeastern city elicited views from parents whose children had died after withdrawal of life support about their priorities and recommendations for PICU end-of-life care. Between one and four years after the death, parents self-administered a written survey including open-ended questions. Content analysis of the responses identified the following priorities for pediatric palliative care, as defined by parents: 1) honest and complete information; 2) ready access to staff; 3) communication and care coordination; 4) emotional expression and support by staff; 5) preservation of the integrity of the parent-child relationship; and 6) faith.¹¹

Clinical Frameworks/Recommendations by Critical Care Professional Consensus. Several major organizations representing critical care professionals have published recommendations related to palliative or end-of-life care in the ICU.

American College of Critical Care Medicine of the Society of Critical Care Medicine. A consensus statement by the Society of Critical Care Medicine (SCCM)'s American College of Critical Care Medicine (ACCM), originally published in 2001 and updated in 2008, provides "Recommendations for end-of-life care in the intensive care unit."¹² This statement includes an extensive discussion of legal and ethical principles relevant to end-of-life care. Many of the recommendations, which are presented in discussion format along with the supporting rationale, relate to processes for withdrawal of life-supporting therapies. For example, it is recommended that clinicians develop "an explicit plan of withdrawing life support" to help "ensure that nothing is overlooked, such as discontinuing routine treatments that provide no comfort to the patient (such as chest radiographs and blood draws)" and to prompt "busy clinicians to make important contacts, such as with social workers, clergy, and organ donation coordinators." These recommendations also cover "support systems and resources for caregivers that address moral distress, burnout, and posttraumatic stress disorder," suggesting that these "may include regular briefings after patient deaths, access to spiritual and psychosocial resources, and relief from responsibilities for some time after a patient dies." In addition, the ACCM's consensus statement sets forth "strategies for improving end-of-life communication in the ICU," including 1) communication skills training for clinicians and 2) ICU family conferences early in the course, according to a

Table 3. Selected Recommendations for End-of-Life Care in the ICU by the American College of Critical Care Medicine of the Society of Critical Care Medicine: "Practical Aspects of Withdrawing Life-Sustaining Treatment"¹²

Every effort should be taken to reassure family members that continuity of clinical care will be maintained.
Clinicians should critically review whether cardiopulmonary monitoring should be continued during withdrawal of

life-sustaining treatments, since it does not provide additional comfort to the patient and is not necessary to assess symptoms of distress.
Once the decision has been made to withhold a life-sustaining therapy (such as renal dialysis or vasopressors), clinicians should critically consider the rationale for continuing any other life-sustaining treatments.
Treatments such as antibiotics, blood products, intravenous fluids and cardiovascular support should be discontinued (after appropriate decision making) without gradual weaning, since no discomfort to the patient will result. Withdrawal of oxygen or ventilatory support should allow time, if needed, to control dyspnea through titration of medication.
Clinicians should solicit input from team members and the family to decide in individual cases whether to leave the endotracheal tube in place when withdrawing mechanical ventilation.

recommended protocol. Selected recommendations from this consensus statement for withdrawing life-sustaining treatment are included in **Table 3**, above.

Table 4. Selected Recommendations (18 of 43) from the American College of Critical Care Medicine Clinical Practice Guidelines for Support of the Family in the Patient-Centered Intensive Care Unit*

- Practitioners fully disclose the patient’s current status and prognosis to designated surrogates and clearly explain all reasonable management options.
- ICU caregivers strive to understand the level of life-sustaining therapies desired by patients, either directly from those patients or via their surrogates.
- Family meetings with the multiprofessional team begin within 24–48 hours after ICU admission and are repeated as dictated by the condition of the patient with input from all pertinent members of the multiprofessional team.
- Nursing and physician staff assigned to each patient are as consistent as possible.
- Families are encouraged to provide as much care as the patient’s condition will allow and they are comfortable providing.
- Family support is provided by the multiprofessional team, including social workers, clergy, nursing, medicine and parent support groups.
- The multiprofessional team is kept informed of treatment goals so that the messages given to the family are consistent, thereby reducing friction between team members and between the team and family.
- A mechanism is created whereby all staff members may request a debriefing to voice concerns with the treatment plan, decompress, vent feelings or grieve.
- Spiritual needs of the patient are assessed by the health care team, and findings that affect health and healing are incorporated into the plan of care.
- Physicians review reports of ancillary team members such as chaplains, social workers and nurses to integrate their perspectives into patient care.
- Open visitation in the adult intensive care environment allows flexibility for patients and families and is determined on a case-by-case basis.
- Visitation in the PICU and NICU is open to parents and guardians 24 hours a day.
- After participation in a previsit education process, visitation by siblings in the PICU and NICU is allowed with parental approval.
- Parents or guardians of children in the ICU are given the opportunity to participate in rounds.
- Whenever possible, adult patients or surrogate decision makers are given the opportunity to participate in rounds.
- The family is educated about the signs and symptoms of approaching death in a developmentally and culturally appropriate manner.
- As appropriate, the family is informed about and offered referral to hospice palliative care and other community-based health care resources.

□ Bereavement services and follow-up care are made available to the family after the death of a patient.

*For this table, we selected those recommendations for family support that are most relevant for palliative care. We excluded recommendations relating to education and competency in knowledge and skills, which will be covered in a separate monograph.

The ACCM also charged a multidisciplinary task force of experts in adult, pediatric and neonatal intensive care to develop evidence-based clinical practice guidelines for support of the family in the patient-centered intensive care unit.¹³ Using Cochrane methodology, this task force conducted an extensive review of published literature and, where strong evidence was lacking, developed a consensus of expert opinion. The guidelines, published in 2007, are organized in ten categories: Decision Making, Family Coping, Staff Stress Related to Family Interactions, Cultural Support of the Family, Spiritual/Religious Support, Family Visitation, Family Environment of Care, Family Presence on Rounds, Family Presence at Resuscitation, and Palliative Care. Guidelines in each of the categories are relevant for ICU palliative care. The ACCM task force endorsed in their entirety the 2004 recommendations (subsequently updated) of the National Consensus Project for Quality Palliative Care. Selected recommendations from this task force are set forth in **Table 4**, above.

Table 5. Examples from Frameworks/Recommendations for Palliative and End-of-Life Care by the American College of Chest Physicians and American Thoracic Society
<p><i>American College of Chest Physicians:</i> “Development of institutional, professional, and regulatory policies to ensure quality palliative and end-of-life care.”</p> <p>-“Every health-care institution should develop policies to guide the staff in addressing the needs of dying patients and their families, the goal being to establish a standard by which the staff is expected to perform.” Examples are “clinical pathways for supportive end-of-life care . . . and policies on advance directives, organ donation, patients’ rights, withholding/withdrawing life support, pain management, conflict resolution, and care of the dying patient.”</p> <p>-“Individual departments within the health-care institution should develop standardized procedures that address specific needs of the dying patient and his/her family. These might include a procedure for respiratory care practitioners and physicians to follow when withdrawing a ventilator. . . . Nursing procedures could address management of pain, anxiety and delirium, organ donation . . . and the care of the patient’s body after death, while at the same time being sensitive to cultural and/or religious practices and customs that might affect such care.”</p>
<p><i>American Thoracic Society:</i> “Withdrawal of mechanical ventilation: decision-making process.”</p> <p>-“Physicians should begin discussions regarding the decision to withdraw mechanical ventilation when patients or their surrogate(s) broach the issue, when health care providers believe that continued mechanical ventilation is no longer meeting the patient’s goals, or it has become more burdensome than beneficial to the patient.”</p> <p>-“Discussions about goals of care and corresponding appropriate level of treatment should be started early . . . in the ICU. Meetings with family should be conducted frequently as the ICU patient’s condition evolves. All curative/restorative treatments should be viewed as time-limited trials and systematically reevaluated to determine if the care plan is achieving its goals.”</p> <p>-“The attending physician should facilitate these discussions, which should take place in a private and personal environment, and involve the patient, all relevant surrogates, and members of the health care team.”</p> <p>-“Once a decision has been made to withdraw mechanical ventilation, a consensus should be reached on when and how this will occur, and who will be present. The family should appreciate that it is difficult to predict how long a patient will continue to breathe after ventilator withdrawal. . . . The family should be told beforehand what they may expect to see and hear during the dying process.”</p>

American College of Chest Physicians and American Thoracic Society. Each of the other major professional societies representing critical care physicians in the U.S., i.e., the American College of Chest Physicians (ACCP) and the American Thoracic Society (ATS), has also issued a statement addressing palliative and end-of-life care for patients with critical illness (**Table 5**, above).^{7,8} As “Components of Palliative and End-of-Life Care for Patients with Cardiopulmonary Disease,” the ACCP’s 2005 position statement⁷ lists ten items in general terms (e.g., “advance care planning” and “relief of distressing symptoms”) within three broader categories: “support for patient and family,” “care of the patient” and “responsibility of the professional caregiver.” The ACCP statement discusses more specific clinician and institution activities and care processes in text. It sets forth the main elements of “a protocol for discussing patient preferences and institution of withholding and withdrawal of life support.” The ATS statement⁸ is based on the broad premise that “all patients receiving curative or restorative health care should receive palliative care concurrently, the elements and intensity of which are individualized to meet the patient’s and family’s needs and preferences.” This statement then discusses recommendations for clinical care with respect to the decision-making process, advance directives, symptom management, withdrawal of mechanical ventilation and bereavement care, among other topics. Examples of recommendations from the ACCP and ATS statements are set forth in **Table 5**.

International Consensus Conference. In 2003, an International Consensus Conference issued a statement titled “Challenges in End-of-Life Care in the ICU.”¹⁴ One of five specific questions addressed by this conference was, “What is the optimal care for patients dying in the ICU?” In this section, the statement emphasizes the essential role of interdisciplinary teamwork for optimal care: “Nurses must be involved in team efforts, they should be encouraged to voice concerns about specific patients and procedures and should be heeded when they do so. It is also important that nurses’ rapport with families be appreciated and supported, since the comfort and satisfaction of the family during the painful dying process often depends on this relationship. Trainee doctors must be encouraged to work with nurses and senior medical staff to offer informed concerned care to patients and families.”

American Association of Critical-Care Nurses. The American Association of Critical-Care Nurses (AACN) endorsed the Clinical Practice Guidelines originally published (2004) by the National Consensus Project on Quality Palliative Care and provides a link to the second edition (2009) of these guidelines on its Web site.¹⁵ Nursing practice recommendations rated according to the level of supporting evidence are included in “AACN Protocols for Practice: Palliative Care and End-of-Life Issues in Critical Care.”¹⁶

Detailed Recommendations for Evaluation and Treatment of Specific Symptoms. Regular assessment and optimal management of pain and other distressing symptoms are included among best practices by all professional organizations addressing palliative care for ICU patients. In addition, more detailed recommendations regarding evaluation and treatment of pain, which continues to be highly prevalent in ICUs,^{17,18} have been separately published in a series of articles by an expert panel convened by the American College of Chest Physicians.^{19–21} The ACCP has also published a comprehensive “Consensus Statement on the Management of Dyspnea in Patients with Advanced Lung or Heart Disease.”²² Although this statement does not specifically address patients with critical illness, its summary of available evidence and recommendations for measurement and treatment with pharmacologic and non-pharmacologic agents are relevant for care of patients in ICUs as well as in other settings.

Distillation of Palliative Care Domains and Recommendations into an Operational Set of Practices That Is Practical for Use in the ICU. As summarized in this monograph, professional groups, patients and families have suggested many practices that may contribute to optimization of ICU palliative care. Some of these are based on rigorous empirical research. Others reflect the judgment of clinical

experts and/or the shared experiences and perspectives of individuals who received treatment for critical illness. Apart from scientific validity, however, *standards for ICU palliative care must also be feasible* for implementation. Feasibility, in turn, depends on: 1) identification of a limited group of standards that those seeking to improve care in a particular institution or ICU consider especially important; 2) operationalization of standards as interventions or practices; and 3) specification of those standards to ensure clarity of interpretation and consistency in performance. Thus, after review of this monograph and references of interest among those we have summarized here, *an initiative to improve ICU palliative care should focus on a small group of well-specified standards that are reasonably achievable* given available resources.

An example of this approach is the “Care and Communication Bundle” of adult ICU palliative care quality measures that are posted with detailed specifications on the National Quality Measures Clearinghouse Web site of the Agency for Healthcare Research and Quality.⁴ As shown in **Table 6**, this measure set focuses on nine basic palliative care processes for the ICU that address key domains of quality as identified by adult patients, their families and critical care professionals (**Table 1**). The measures are triggered by time periods in the ICU, with emphasis on proactive, early performance of key processes (e.g., identify medical decision maker and resuscitation status before Day 2 in the ICU). Specifications are precise (e.g., the family meeting measure specifically defines “interdisciplinary” and also provides that the “family meeting,” as documented in the medical record, must include discussion of prognosis, goals of care and the patient’s and family’s needs and preferences). These measures were developed and extensively tested in a broad range of ICUs in the Transformation of the ICU performance improvement project of the Voluntary Hospital Association (VHA), Inc.³ An ongoing ICU–palliative care initiative in medical ICUs in Veterans Integrated Service Network 3 is focused on these measures.^{23, 24} Measures addressing other care processes and structural aspects of care have also been proposed.²⁵

Table 6. Adult ICU Palliative Care Processes Measured in the Voluntary Hospital Association’s “Care and Communication Bundle”^{3, 4}
Identify the patient’s health care proxy (or other appropriate surrogate)
Determine whether the patient has an advance directive
Clarify the patient’s resuscitation status
Assess pain regularly using an appropriate scale
Manage pain optimally
Offer social work support to the patient/family
Offer spiritual support to the patient/family
Conduct a meeting of the interdisciplinary team with the family

The Role of Standards in an ICU Palliative Care Initiative. Reflecting the strength of their commitment to improving palliative care in the ICU setting, all major societies representing critical care professionals have devoted significant effort to development of standards for clinical practice in this area. The resulting guidelines and recommendations, which we have briefly surveyed in this monograph, share many common elements. They are also generally consistent with standards established by the National Consensus Project for Quality Palliative Care and the National Quality Forum for palliative care across clinical settings. They overlap with definitions of high-quality palliative care by patients receiving treatment in ICUs and their families. However, few of these standards for the ICU have been made operational for implementation. Nor are standards, even those that are in operational form and accompanied by clear specifications, sufficient by themselves for important and sustainable changes in clinical practice. A successful improvement effort requires in addition: 1) well-designed work processes

that facilitate clinical performance; 2) an institutional/ICU culture that values and supports the effort; and 3) education of the health care team about the scientific and clinical rationale for the effort and about knowledge and skills needed for performance.²⁶ Identification of a limited group of standards that are important and achievable within a specific clinical setting is a significant first step for every ICU palliative care initiative.

SUMMARY OF KEY POINTS ABOUT STANDARDS FOR ICU–PALLIATIVE CARE IMPROVEMENT:

1. Important “stakeholders,” including ICU patients, families and professional groups, generally agree on domains of high-quality palliative care for the critical care setting.
2. The field would benefit from consensus on basic standards that are made operational and are clearly specified and feasible for consistent clinical implementation.
3. The National Quality Measures Clearinghouse of the Agency for Healthcare Research and Quality posted the Voluntary Hospital Association’s “Care and Communication Bundle” of nine care process measures, which has served as the basis for several ICU palliative care improvement efforts.
4. Within each ICU, successful implementation of standards will depend on well-designed work processes, staff education and a culture supporting high-quality, interdisciplinary palliative care.

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