



**Evaluation of ICU Palliative Care Quality:
A Technical Assistance Monograph from The IPAL-ICU Project**

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Introduction. Quality improvement depends on the ability to assess and monitor performance. Thus, a successful initiative to improve ICU palliative care will entail evaluation using appropriate measures. In this monograph, we address approaches to measurement of quality, domains that are relevant for evaluating palliative care in ICU settings, specific measures, and methods for implementing quality measurement to achieve performance improvement.

Approaches to Quality Measurement. The model described by Donabedian,¹ identifying *structure*, *process*, and *outcome* components of quality, is widely used as a framework for evaluating health care, including ICU care.^{2,3} *Structural measures* address material resources and organizational aspects of care (e.g., availability of a palliative care consultation service). *Process measures* focus on the actions of professional caregivers, their clinical and nonclinical processes and procedures (e.g., regular assessment of symptoms); they reflect the extent to which delivery of care is based on the best available evidence. *Outcome measures* evaluate the results that are achieved (e.g., family satisfaction). The Johns Hopkins Quality and Safety Research Group adds to this model a fourth component, *culture*, referring to local norms, attitudes and values (e.g., interdisciplinary collaboration as perceived by ICU team members).⁴ Pros and cons for using each of these types of measures are summarized in **Table 1**. Recent initiatives for ICU performance improvement, including ICU palliative care improvement efforts by the Voluntary

Table 1. Advantages and Disadvantages of Different Quality Measures

TYPE OF QUALITY MEASURE	ADVANTAGES	DISADVANTAGES
Structure	<ul style="list-style-type: none"> ● Relatively easy to measure 	<ul style="list-style-type: none"> ● Minimum standard ● Not responsive to ongoing effort
Process	<ul style="list-style-type: none"> ● Activities actionable by clinicians ● Face validity for clinicians ● Relatively easy to measure ● No burden for patients/families ● Minimal need for risk adjustment ● Interpretable feedback for team 	<ul style="list-style-type: none"> ● Do not measure results of care ● Evidence of linkage to outcome often difficult to obtain
Outcome	<ul style="list-style-type: none"> ● Important to patients and families 	<ul style="list-style-type: none"> ● Risk adjustment difficult ● Hard to measure ● May be influenced by factors beyond clinicians' control ● Not well correlated with structure/process measures in palliative care
Culture	<ul style="list-style-type: none"> ● Essential for sustained success in quality improvement ● Data from and to ICU team ● Responsiveness shown for safety culture assessments 	<ul style="list-style-type: none"> ● To date, no formal tool specifically to evaluate culture supporting palliative care

Hospital Association (VHA), Inc., and by Veterans Integrated Service Network (VISN) 3 have relied mainly on process measures, which have a number of important advantages; they: 1) focus on activities that are actionable by clinicians; 2) face validity for clinicians; 3) are suitable for clinician performance feedback; 4) are relatively independent of adjustment for patient or family characteristics or preferences; 5) are practical; 6) are generally more responsive to improvement

efforts than other types of measures; and 7) are minimally burdensome for patients and families. For validity, however, process measures should be correlated with outcomes valued by patients, families and/or clinicians. Key attributes of all types of measures include reliability, feasibility and acceptability, as well as validity and importance.^{5,6}

Domains for Measurement of ICU Palliative Care Quality. Table 2 lists ICU palliative care quality domains as defined by expert consensus⁷ and by ICU patients and families.⁸ Definitions from these different perspectives are overlapping and are also consistent with those established by the National Consensus Project for Quality Palliative Care as a framework for clinical practice guidelines and preferred practices for palliative care professionals.⁹ A recent study used focus groups of (recovered) ICU patients, families of survivors and families of

Table 2. Domains of ICU Palliative Care

Source	Domains of Care
<i>Professional Consensus (Critical Care Peer Workgroup of Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care Program)</i> ⁷	<ul style="list-style-type: none"> • Symptom management and comfort care • Patient- and family-centered decision making • Communication within the team and with patients and families • Emotional and practical support for patients and families • Spiritual support for patients and families • Continuity of care • Emotional and organizational support for ICU clinicians
<i>ICU Patients and Families</i> ⁸	<ul style="list-style-type: none"> • Timely, compassionate, clear communication by clinicians • Patient-focused medical decision making • Patient care maintaining comfort, dignity, personhood, privacy • Proximity of families to patients • Interdisciplinary support of family including bereavement care

patients who died in the ICU to elicit their views of key components of high-quality palliative care in adult critical care settings.⁸ In a diverse cohort of forty-eight participants in nine focus groups in three locations across the country who had been exposed to different types of ICUs, hospitals and local environments, there was broad agreement that high-quality palliative care in the adult ICU includes the following: 1) *communication by clinicians* that is timely, clear and compassionate; 2) *clinical decision making that is focused on patients' preferences, goals and values*; 3) *patient care maintaining comfort, dignity, personhood and privacy*; 4) *open access and proximity of families to patients*; and 5) *interdisciplinary support of families* during the critical illness and, for families of patients who died in the ICU, in the bereavement period. Critical care professionals have also highlighted *emotional and organizational support for ICU clinicians* and *continuity of care* as important domains of ICU palliative care quality. Health care providers and society as a whole place value on efficient utilization of critical care resources, which are scarce and expensive. Although not a direct reflection of the quality of palliative care, measures within the utilization domain are relevant and responsive to an ICU palliative care initiative, as discussed more fully below.

Specific Measures. Domains of quality are made operational as specific measures, each with a numerator and a denominator. In general, the denominator defines the target population—e.g., all patients admitted to the ICU during a certain time period, or a subset of ICU patients with selected characteristics. The numerator represents the care process (or outcome or structure)

that will be evaluated as an indicator of quality. Both the denominator and the numerator must be carefully specified.² For this purpose, the following considerations are relevant:

► *Choosing the Denominator.* Although the entire ICU population may in theory be appropriate as a denominator for many palliative care measures, it may not be feasible to collect such a large volume of data, particularly if the method of collection is a manual review of medical records. Typically, then, it is more practical to select subgroups with special risks or needs. For evaluation of palliative care, subgroups can be defined to select patients at greatest risk of hospital mortality or significant impairment of function or cognition, such as those with high severity of illness, specific diagnoses (e.g., cancer, global cerebral ischemia, multiple organ failure of extended duration) or prolonged ICU stay; examples of denominators for ICU palliative care measures are provided in **Table 3**. The denominator for some measures may be more appropriately expressed in terms of a time period of patient care (e.g., a patient day, or nursing care interval of specified hours). For example, evaluation of the quality of pain assessment might focus on the proportion of intervals in which the nurse assessed the patient's level of pain.

Table 3. Examples of Denominators for ICU Palliative Care Quality Measures

● Patients in the ICU for \geq specified number of days (e.g., 3 or 5)
● Patients with high severity of illness (e.g., APACHE II score \geq specified number)
● Patients with prolonged (e.g., >3 days) dysfunction of multiple organs
● Patients with evidence of global cerebral ischemia
● Patients admitted to ICU after >7 days in hospital

► *Choosing the Numerator.* In selecting numerators for quality measures, the main considerations are 1) the strength of the scientific evidence supporting measurement, 2) the importance of the practice to key stakeholders and 3) the feasibility of collecting the measure given existing resources.⁴ Care processes are appropriate indicators if correlated—ideally through rigorous empirical research—with desired outcomes. Although such evidence is difficult to obtain for many processes (even in well-established fields of investigation like cardiology), some ICU palliative care processes are solidly supported. For example, several studies using rigorous methods have linked proactive meetings between clinicians and ICU families with a variety of important, favorable outcomes, including family satisfaction, consensus about care goals, family psychological well-being and efficient utilization of critical care resources.^{10–12} In addition, processes like frequent assessment and effective management of pain, which are mandated by the Joint Commission on the basis of existing evidence and fundamental compassionate principles, are appropriate for evaluation in a quality improvement initiative. Care processes that were specifically endorsed as indicators of high-quality ICU palliative care by a consensus among adult patients and families participating in focus groups across the U.S.⁸ are set forth in **Table 4**. Referral for palliative care specialty consultation, where available, is another relevant care process for quality monitoring.

Table 4. Care Processes Endorsed by ICU Patients and Families as Palliative Care Quality Indicators⁸

- Regular family meetings with attending physician and nurse
- Early identification of surrogate decision maker/advance directive/CPR status
- Frequent assessment of pain and titration of analgesia to maximize comfort and achieve desired level of consciousness
- Offer of pastoral care with sensitivity and without mandate
- Offer of practical assistance and emotional support
- Distribution of printed information about ICU for families
- Offer of bereavement support to families of patients dying in the ICU

The danger of “perfect defeating good” is very real in the selection of indicators. Even if multiple processes are relevant and worthy of measurement, an exhaustive set of measures can become so burdensome to collect that data quality is compromised or the project is abandoned. The target, then, should be *a few good measures* that allow reasonable evaluation of some—not all—important aspects of care.

Existing Measures. In several areas of ICU practice (e.g., management of mechanically ventilated patients or those with sepsis), performance improvement has been approached by grouping evidence-based processes as “bundles” of measures that are applied together for a fuller assessment of the quality of care.^{13–15} The “Care and Communication Bundle,” developed as part of the national Transformation of the ICU (TICU) program by the Voluntary Hospital Association (VHA), Inc., uses this approach to measure ICU palliative care quality in adult ICUs.¹⁶ This measure set evaluates nine evidence-based care processes, listed in **Table 5**, below, addressing established quality domains. To promote feasibility, the population targeted by the denominator for most of the measures is limited to patients in the ICU for at least five days (a practical marker of risk for poor outcome among critically ill adults). Individual care processes are triggered by specified days after admission to the ICU, with some processes to be performed by Day 1 and others by Day 3 or Day 5. This time-triggered strategy is designed to prompt timely performance of important processes for all ICU patients while limiting the burden of data collection to patients with prolonged ICU stays. The VHA “Care and Communication Bundle” is posted on the National Quality Measures Clearinghouse Web site maintained by the Agency for Healthcare Research and Quality, together with detailed specifications for the numerator and denominator of each measure.¹⁷ A data collection instrument for use with these measures is available on the IPAL-ICU Web site.¹⁸ The “Care and Communication Bundle” was the basis for a large-scale collaborative improvement effort by multiple ICUs in the VHA TICU program, by a major faith-based hospital system and by medical ICUs in all acute-care hospitals in the Veterans Integrated Service Network 3. To this group of measures, several other measures were added by a consensus group of critical care professionals, including measures of continuity of care and of support for critical care clinicians caring for dying patients.¹⁹

Sources of Data for Quality Measurement. Potential sources of data for palliative care quality measurement include 1) medical records, 2) administrative databases or 3) direct interviews of patients, families or clinicians. These data sources are addressed here.

Medical Records. Most quality measures are collected by manual review of patient charts. This method relieves patients and families of the burden to provide data, but can be burdensome for the reviewer, especially if multiple measures are implemented and if the documentation does not clearly reflect the relevant data elements. In many ICUs, staff members

assigned to quality measurement also have other responsibilities and limited time. Another issue regarding medical records is that the documentation they contain may not accurately reflect

Table 5. Voluntary Hospital Association’s “Care and Communication Bundle” of Palliative Care Process Measures for Adult ICUs*

*Unless otherwise indicated, the denominator for each of these measures is the number of patients with ICU stay ≥ 5 days.

actual practice. It is usually impractical, however, to observe clinical behaviors directly, or to interview patients, families or even clinicians, and interview data are subject to other biases. In any event, the medical record is the central venue for exchange of accurate information among multiple clinicians caring for a critically ill patient and, as such, is an appropriate source of data in evaluating the quality of this care. To evaluate clinician communication with families about patient care preferences and goals, for example, it is appropriate and reasonable to use medical record documentation as the data source; besides the meeting itself, documentation is also

QUALITY INDICATOR	NUMERATOR FOR QUALITY MEASURE
1. Medical Decision Maker Documentation of efforts to identify a medical decision maker (family member or other appropriate surrogate) for the patient on or before Day 1 in ICU	<i>Numerator:</i> Number of patients who have documentation of ICU efforts to identify a health care proxy (or other appropriate surrogate decision maker) on or before Day 1 of the ICU admission
2. Advance Directive Documentation of advance directive status on or before Day 1 in ICU	<i>Numerator:</i> Number of patients who have documentation of advance directive status on or before Day 1 in ICU
3. Resuscitation Status Documentation of resuscitation status on or before Day 1 in ICU	<i>Numerator:</i> Number of patients who have documentation of resuscitation status on or before Day 1 in ICU
4. Family Information Leaflet Documentation of information leaflet distribution to ICU family members on or before Day 1 in ICU	<i>Numerator:</i> Number of patients whose families were personally given a printed information leaflet by an ICU team member on or before Day 1 in ICU
5. Pain Assessment Regular pain assessment	<i>Numerator:</i> Total number of 4-hour intervals (on Day 0 and Day 1 in ICU) for which pain was assessed and documented <i>Denominator:</i> Total number of 4-hour intervals (on Day 0 and Day 1 in ICU) for patients with an ICU length of stay ≥ 5 days (this number cannot be greater than 12)
6. Pain Management Optimal pain management	<i>Numerator:</i> Total number of 4-hour intervals (on Day 0 and Day 1 in ICU) for which the documented pain score was ≤ 3 <i>Denominator:</i> Total number of 4-hour intervals (on Day 0 and Day 1 in ICU) with numerical pain values of 0 to 10, for patients with an ICU length of stay ≥ 5 days (this number cannot be greater than 12)
7. Social Work Support Social work support offered to ICU patients and/or families on or before Day 3 in ICU	<i>Numerator:</i> Number of patients who have documentation in the medical record that social work support was offered to the patient and/or family on or before Day 3 in ICU
8. Spiritual Support Spiritual support offered to ICU patients and/or families on or before Day 3 in ICU	<i>Numerator:</i> Number of patients who have documentation in the medical record that spiritual support was offered to the patient and/or family on or before Day 3 in ICU
9. Interdisciplinary Family Meeting Adequate clinician–patient/family communication on or before Day 5 in ICU	<i>Numerator:</i> Number of patients who have documentation in the medical record that an interdisciplinary family meeting was conducted on or before Day 5 in ICU

necessary to ensure that the content of an ICU family meeting is known to all members of the care team. Data collection may be easier with electronic medical records, but these do not always

have structured elements (particularly those relevant to palliative care) to facilitate review.⁴ The presence of data in required fields—for example, electronic records in some institutions contain a specific field for documentation of cardiopulmonary resuscitation (CPR) status for all patients—can serve as an indicator of the quality of palliative care, ideally prompting both discussion and documentation of CPR status on a timely and reliable basis.

Administrative Databases. Administrative data are useful in several areas of measurement relevant to ICU palliative care. One is evaluation of resource utilization—specifically, lengths of stay in the ICU and hospital, which have been favorably affected (shortened) in past studies of ICU palliative care interventions such as proactive communication and referral for palliative care specialty consultation.^{11, 20, 21} Administrative databases can also be used to select patient subgroups for closer evaluation. For example, an assessment of ICU palliative care quality might focus on patients with advanced age, prolonged ICU stay, admission to the ICU from a nursing home or after a prolonged hospital ward stay, multiple admissions to the hospital over the previous six months, or particular diagnoses, or on patients who died in the ICU or hospital; any of these groups would usually be identifiable from administrative data. In addition, data on vital status at discharge are useful in monitoring for unintended harmful consequences—such as higher mortality in the ICU or hospital—of a palliative care improvement effort. In past initiatives, stable mortality rates despite shorter time to limitation of life support provided reassurance that no new deaths were occurring as a result of more timely discussion and deliberation about relative benefits and burdens of intensive care therapies.^{11, 12}

Patients and Families. Impairments of consciousness and capacity preclude data collection from ICU patients with the highest acuity of illness—precisely the ones from whom perspectives relevant to palliative care would be most valuable. In neonatal and pediatric ICUs, similar challenges are common. Family-focused outcomes such as satisfaction, psychological well-being and comprehension of information that is communicated by clinicians are of great interest in evaluating the quality of palliative care. Unfortunately, they are also very difficult to collect, particularly in ICU settings, where the time window for direct interviews or survey administration is often short and families are distressed and distracted by the patient’s critical illness. Valid tools exist to measure ICU family satisfaction (Family Satisfaction in the ICU questionnaire;^{22, 23} Critical Care Family Satisfaction Survey²⁴) and various components of psychological well-being (e.g., Hospital Anxiety and Distress Scale;²⁵ Impact of Events Scale of post-traumatic stress²⁶), but these tools are more suitable for research than for routine, ongoing monitoring of quality. To complement other measures of palliative care quality collected from medical records and administrative data, it may be practical periodically to select a small number of items for use in surveying families, either in the ICU or by telephone after discharge. Most, although not all, institutional review boards will exempt this type of activity from the requirement of informed consent, provided the data are solely for quality improvement.^{27–29} In some large health care systems, like the Department of Veterans Affairs (VA) system, data elements relevant to palliative care, such as the after-death survey of bereaved families,³⁰ are routinely collected. These data have been used to measure palliative care quality and provided as feedback to palliative care consultants in VA hospitals, but they are difficult to interpret for a focused assessment of care in a specific setting like the ICU, as opposed to an overall assessment of care from hospital admission to discharge.

Clinicians. Clinicians’ perspectives on the experience of patients, on their own experience, and on the “culture” of the ICU contribute to an overall assessment of palliative care

quality and are easier to collect than data from patients and families. *Patient Experience*. A version of the Quality of Dying and Death (QODD) tool³¹⁻³³ was developed for assessments by ICU nurses and has been used in two studies of interventions to improve the quality of ICU palliative care.^{34, 35} In one study, the QODD score was unchanged, although the intervention had a favorable impact by other measures;³⁵ in the other study, the intervention was associated with a modest improvement in QODD.³⁴ *Clinician Experience*. Several studies have documented a high prevalence of moral distress and burnout among intensive care physicians and nurses.³⁶⁻³⁹ Since this phenomenon has been attributed in part to the emotional stresses of caring for dying patients and of providing therapies for which burdens may at times seem to outweigh benefits, it is reasonable to hypothesize that an ICU palliative care improvement effort might measurably affect burnout and/or related outcomes such as job satisfaction or staff retention. To date, however, no study of this kind has been reported. *ICU Culture*. Efforts to improve ICU safety focus on “culture,” which is assessed by evaluating staff attitudes toward patient safety and teamwork climate.⁴ Although no formal tool currently exists to measure the extent to which an ICU’s culture supports high-quality ICU palliative care, informal debriefings about communication, teamwork and other issues across all disciplines on the ICU team may provide valuable information about the progress of a quality improvement effort.⁴ *Overall Quality*. A ten-item tool eliciting nurse and physician ratings of various aspects of ICU palliative care quality was piloted in academic centers across the U.S. (Curtis JR, personal communication). A review of similarities and differences between ratings by different disciplines in the same ICU, as were found in pilot testing of this tool, might be useful as a basis for promoting interdisciplinary collaboration to improve care.

Implementing Quality Measures as Part of a Performance Improvement Initiative.

A pitfall of quality initiatives is overemphasis on measurement with relative neglect of the activities that are required to achieve quantifiable improvement. As an old proverb points out, “You can’t fatten a calf by weighing it.” To improve quality in any area, including palliative care, all of the following questions must be addressed as part of implementation of an improvement effort: 1) What changes in clinical practice or clinician behavior are needed? 2) What changes in documentation will facilitate and reflect improvements expected from clinical changes? 3) How can work processes and systems be redesigned or created to support improvement? 4) How will performance be measured? 5) How will feedback on performance be provided to the team? For example, since clinicians generally must attempt cardiopulmonary resuscitation in the absence of a specific directive to withhold it, but some patients prefer withholding of CPR (i.e., DNR), an ICU might seek to increase the proportion of patients for whom resuscitation status is addressed (either confirming that resuscitation should be attempted or authorizing a do-not-resuscitate directive) early in the stay. A clearly specified measure exists to evaluate performance of this care process,^{16, 17} and other measures might also be collected, such as the relative distribution of full resuscitation and do-not-attempt-resuscitation directives, and the time (number of days from ICU admission) to documentation of resuscitation status. But performance on these measures is unlikely to improve until the ICU specifically assigns responsibility for discussing resuscitation status to the appropriate member(s) of the team; trains the responsible individuals as needed to do this; develops a simple system to trigger attention to this task and remind staff until completion; identifies an area within existing forms or creates a new one to document the discussion; determines who will review the record to collect data on the measure; and establishes a mechanism for apprising the team of progress and ongoing opportunities for improvement. Optimal performance will also require that staff members are educated about why the effort is important and are engaged collaboratively in planning and

implementation. In recent efforts to improve patient safety in ICUs (e.g., reduction of catheter-related bloodstream infection), which achieved unprecedented successes at very low cost in terms of personnel and technical resources,⁴⁰ the use of sound, well-specified and feasible measures was carefully integrated in a larger program of education, system supports and locally (i.e., unit-) focused activities to build a conducive culture and effective relationships across disciplines on the ICU team.⁴ This approach⁴¹ provides a helpful model for ICU palliative care initiatives.

Conclusion. In a national survey reported in 2006, physician and nurse directors of ICUs strongly endorsed quality monitoring as an effective strategy for optimizing ICU palliative care.⁴² The survey highlighted low utilization of this strategy, which was then available in only approximately one-quarter of ICUs led by the responding directors. More recently, measures for routine monitoring, feedback and improvement of the quality of ICU palliative care have been published with detailed specifications^{16, 17} and multi-ICU collaboratives have implemented such measures, sharing methods and tools.^{16, 43} Meanwhile, research to inform best clinical practices in this area is moving forward, as is the science of performance improvement.⁴⁴ These resources should enhance and facilitate new initiatives, which in turn will develop strategies to address challenges in specific institutions and ICUs while also expanding the pool of resources to support future efforts.

SUMMARY OF TEN KEY STEPS FOR IMPLEMENTING QUALITY MEASUREMENT AS PART OF AN ICU-PALLIATIVE CARE IMPROVEMENT INITIATIVE:

1. Identify problem/need that justifies investment of resources in an ICU-palliative care improvement project.
2. Convene a project team including the physician and nurse directors of the ICU.
3. Choose up to three areas as initial targets for the improvement effort.
4. Enlist support of hospital leadership.
5. Select/specify quality measures that are evidence-based and feasible for use in evaluating care.
6. Pilot measures in baseline evaluation of care.
7. Engage ICU team in review of baseline performance and discussion of barriers and strategies for improvement.
8. Set achievable short- and medium-term goals for the initiative; define intervals for follow-up evaluation.
9. Identify/implement changes in clinical practice and documentation that are needed to achieve goals.
10. Conduct follow-up evaluation.

After each evaluation, repeat steps 7 through 10. As performance improves, stretch the goals.

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