

**Seven End-of-Life Care Domains
Associated Quality Indicators
and
Related Clinician and Organizational Interventions/Behaviors**

These domains, quality indicators and interventions or behaviors were generated in a modified Delphi approach as described in the following article:

Clarke EB, Curtis JR, Luce JM, Levy M, Nelson J, Solomon MZ, for the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup Members. Quality indicators for end-of-life care in the intensive care unit. **Critical Care Medicine** 2003, in press.

The items under each domain represent potential suggestions for clinician and/or organizational interventions or behaviors that may improve the quality of end-of-life care in the ICU setting. Most of these interventions or behaviors have not been tested in randomized trials and the majority of them represent expert clinician opinion.

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The quality indicators under each end-of-life-care (EOLC) domain are in bold print and the clinician and organizational interventions/behaviors associated with the quality indicators are the bulleted items.

Domain 1 - Patient and Family Centered Decision Making

Recognize the patient and the family as the unit of care:

- Assess and document who comprises the family; it may not be a traditional one.

Assess the patient's and family's decision-making style and preferences:

- Clarify and document level of participation patient and/or family desire in choosing treatment options.

Address conflicts in decision making within the family and between staff and family:

- Explicitly address conflicts that arise within families and help families resolve these conflicts.
- Explicitly address conflicts that arise between staff and family members.
- Train staff in conflict resolution techniques.

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:

- Take the lead in involving patient and/or family in treatment decisions by convening a family conference with members of the health care team and available family members. If patient is able to participate, hold conference at the bedside.

Clarify and document the status of the patient's advance directive:

- If the patient has completed an advance directive, review with the patient and/or family upon admission to the ICU and document discussion.
- Place the advance directive in the chart and "flag" the chart.

Identify the health care proxy and surrogate decision-maker:

- For patients who lack decision-making ability, assess and document the family's knowledge of the patient's verbal wishes and goals about treatment.

Clarify and document resuscitation orders:

- Distinguish do-not-resuscitate (DNR) orders from withholding and withdrawing life-sustaining treatment; policies and guidelines for these should be distinct.
- Document discussions with patient and/or family about cardiopulmonary resuscitation (CPR).

- Utilize preprinted “family discussion sheet” where informal and formal discussions with family members may be documented.

Assure patients and families that decision-making by the health care team will incorporate their preferences.

Follow ethical and legal guidelines for patients who lack both capacity and a surrogate decision-maker:

- Establish a written policy detailing these guidelines.

Establish and document clear, realistic and appropriate goals of care in consultation with the patient and family:

- Ensure that treatments reflect the goals of care.
- Identify a time frame for the reassessment of treatment goals and set up follow-up meetings with the patient and/or family to discuss progress towards goals.

Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient condition changes.

Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected:

- Develop pathways to improve the quality of care in the setting of withdrawing life-sustaining treatments.

Domain 2 - Communication within the Team and with Patients and Families

Meet as an interdisciplinary team to discuss the patient's condition, clarify goals of treatment and identify the patient's and family's needs and preferences:

- Develop an ICU policy which includes standards for communication with patients and families.

Address conflicts among the clinical team prior to meeting with the patient and/or family:

- Develop an EOLC critical pathway with checkboxes for communication items e.g., interdisciplinary team meetings and patient/family and clinician meetings (formal and informal).

Utilize expert clinical, ethical and spiritual consultants when appropriate:

- Develop methods to provide access to these consultants.
- Document offering families the opportunity to meet with these consultants.
- Document involvement of the consultants in care of the patient and family.

Recognize the adaptations in communication strategy required for patients and families according to the chronic versus acute nature of illness, cultural and spiritual differences and other influences:

- "Stage" the delivery of distressing news to patients and/or families.
- Involve spiritual and cultural experts or consultants in staff education and in care of patients and families.

Meet with the patient and/or family on a regular basis to review patient's status and answer questions:

- Add communication category on preprinted physician's and nurse's narrative forms to cue clinician attention to communication.
- Allow sufficient time for meeting of patient and/or family with the health care team, particularly for the initial discussion of goals of care.
- Involve the attending physician in this initial meeting.
- Set up a schedule for future meetings with patient and/or family to review patient's status.

Communicate all information to patients and families, including distressing news, in a clear, sensitive, unhurried manner and in an appropriate setting:

- Meet in a quiet private area with adequate seating.
- Introduce everyone who is present.
- Explain reason for meeting.
- Avoid euphemisms and medical jargon.
- Discuss the patient's prognosis and realistic treatment goals frankly, but simultaneously demonstrate caring and empathy for the patient and family.

- Engage in informal de-briefing with team members following patient and/or family meetings to clarify understandings and solicit constructive feedback (e.g. “How do you think it went? What did I miss?”)
- Develop and send a *Clinician Communication Evaluation* survey to family three months after the patient’s death as part of an EOLC continuous quality improvement (CQI) effort.

Clarify the patient’s and family’s understanding of the patient’s condition and goals of care at the beginning and end of each meeting:

- Make eye contact.
- Listen.
- Acknowledge strong emotions.
- Ask if there are additional questions or concerns.
- Ask if there is any conflict within the family about the goals of care and treatment options.

Designate primary clinical liaison(s) who will communicate with the family daily:

- Ensure that the patient and/or family know who the primary clinical liaison(s) are and how to contact them.

Identify a family member who will serve as the contact person for the family:

- Document the primary contact and additional contacts in the medical record.

Prepare the patient and family for the dying process:

- Develop and distribute written material to help patients/and or families understand what to expect as death approaches.
- Emphasize the comfort care that will be given to the patient rather than the withholding and/or the withdrawal of life-sustaining treatment.
- Be explicit about symptom management strategies.

Domain 3 - Continuity of Care

Maximize Continuity of care across clinicians, consultant and settings:

- Consider a policy of compassionate non-discharge/non-transfer of the patient from the ICU if the patient's death is a reasonable expectation within the ensuing 12-48 hours, and if the patient and/or family desire it.
- Identify primary care team to maintain/facilitate continuity of care across nurses, physicians, therapists etc.

Orient new clinicians regarding the patient and family status:

- If the patient transferred from the ICU, ensure orders are consistent with the plan of care in the ICU and that a comprehensive report is given to new clinicians.
- Ensure that needed equipment is available on the unit to which the patient is transferred.
- Ensure that the patient's code status is included in reports, during transfers to procedure areas and transfers to other services.

Prepare the patient and/or family for a change of clinician(s) and introduce new clinicians:

- Include new clinicians in family meetings to provide a "bridge" and enhance continuity of care.
- Include questions on the family's *Clinician Communication Evaluation* survey about the effectiveness of the team during the transition of clinicians, and the perceived continuity or disruption of care.

Domain 4 – Emotional and Practical Support for Patients and Families

Elicit and attend to the needs of the dying person and his/her family:

- Attending MD and other clinicians continue to meet with the family of a dying patient as appropriate to emphasize comfort care and to convey non-abandonment.

Distribute written material (booklet) for families that includes: orientation to the ICU environment and open visitation guidelines; logistical information (nearby hotels, banks, restaurants, directions, etc.); listings of financial consultation services; and bereavement programs and resources:

- Develop written materials described above.
- Ensure consistency in the distribution of these written materials.
- Develop guidelines for children and pet visitation.

Facilitate strengthening of patient-family relationships and communication:

- Support open visitation to accommodate patient and family needs.
- Talk to patient and/or family about young children's and grandchildren's needs and provide appropriate supportive referrals.
- Encourage family and loved ones to talk to the patient regardless of the patient's level of consciousness.
- Clarify family's desired level of involvement in patient's physical care and involve as appropriate.
- Reduce unnecessary patient sedation, while ensuring adequate treatment of pain and anxiety.
- Use consistent scoring system for assessing and titrating sedation.
- Provide access to telephones for patient and family.
- Consider making pager or beeper system available to family members so they may leave the ICU more comfortably knowing that they can be reached quickly, or document family cell phone and pagers in the medical record for easy access.
- Consider offering a toll free number to patients and families to facilitate long distance calls.

Maximize privacy for the patient and family:

- Move the patient to the most private area of the ICU.
- Consider transfer of the patient from the ICU for more privacy, if feasible and desired by the patient and family.
- Provide comfortable chairs for family members in the patient's room.
- Provide a private room with toilet articles near the ICU for family to place their belongings, wait and rest .

Value and support the patient's and family's cultural traditions:

- Provide staff with an overview of various cultures' significant rituals around death and dying.
- Allow for cultural differences in dying rituals and body care after death whenever possible.
- Arrange culture mediators and/or consultants where appropriate.

Arrange for social support for dying patients without family or friends:

- If patient wishes and is conscious, request appropriate pastoral care representative or trained volunteer to visit.

Distribute written material (booklet) to families containing listings of bereavement support programs/resources:

- Ensure consistency in distribution of these materials.

Support the family through the patient's death and their bereavement:

- Clinicians lend their physical presence and support to the dying patient and family, whenever requested.
- Explore the family's wishes about being at the bedside if life-support withdrawn and/or during the dying process.
- Discuss issues of funeral arrangements, release of the patient's body etc. (if possible and appropriate) prior to death so that during the dying process and immediately after, the family does not need to make these decisions and may have a quiet time.
- Provide a private room for the family after the patient's death.
- Give family the opportunity to meet with the health care team after the patient dies.
- Send a preprinted card of condolence signed by the health care team to the family after the patient dies.
- Consider making phone contact with the family one month after the patient's death, if circumstances permit.

Domain 5 – Symptom Management and Comfort Care

Emphasize the comprehensive comfort care that will be provided to the patient rather than focus on the removal of life-sustaining treatments:

- In initial clinical team meetings and subsequent discussions with the patient and/or family, enumerate interventions which can and will be provided to alleviate the patient's distressing symptoms, promote patient comfort, maintain patient dignity and maximize privacy for the patient and the family.
- Inform the patient and/or family about the open visitation policy, availability of spiritual resources and cultural supports and how to access clinician liaison(s) if questions or concerns arise.
- Create and institute a preprinted physician Comfort Care Order form.
- Inquire about specific interventions, e.g., spiritual, physical, practical and emotional measures that would be comforting and meaningful to the dying patient and/or their family.
- Include the above individualized comfort care measures on the preprinted physician Comfort Care Order form.

Institute and use uniform quantitative symptom assessment scales appropriate for communicative and non-communicative patients on a routine basis:

- PAIN ASSESSMENT – a) communicative patients – consider using numerical rating scale(NRS), (0-10) or Baker Wong Faces scale; b) non-communicative patients – consider using a Behavioral Pain Assessment Scale(BPAS).
- AGITATION ASSESSMENT – for both communicative and non-communicative patients – consider using either the Ramsey Scale, Riker Sedation-Agitation Scale(SAS), Motor Activity Assessment Scale(MAAS) or Vancouver Interaction and Calmness Scale(VIC).
- DELIRIUM and CONFUSION – a) communicative patients – consider using either the Mini-Mental State Exam(MMSE) or Memorial Delirium Assessment Scale(MDAS); b) non-communicative patients – consider using either the Confusion Assessment Method for ICU (CAM-ICU), Delirium Rating Scale(DRS) or modified Memorial Delirium Assessment Scale(MMDAS).
- Pain assessment section/category can be incorporated into preprinted and/or computerized ICU flowsheets, preprinted MD and RN ICU admission forms, preprinted MD and RN narrative notes and physician Comfort Care Order form.

Standardize and follow best clinical practices for symptom management:

- SYMPTOM MANAGEMENT:
 - Prepare ICU policies establishing interdisciplinary accountability for symptom assessment and management.

- Follow the Joint Commission for the Accreditation of Health Care Organizations' (JCAHO) 2001 Pain Management Standards and Intents.
- Prepare clinician pain management guidelines which include:
 - . Dosing for opioid naive and opioid tolerant patients;
 - . Equianalgesic conversions;
 - . Usefulness of round-the-clock dosing;
 - . Recommended pharmacologic treatment of both nociceptive pain (including procedural pain) and neuropathic pain.
- Modify flowsheets to include additional spaces for the assessment of pain intensity scores for multiple pain sites/locations, interventions and responses to interventions.
- Develop preprinted ICU protocols and standing orders for the management of pain, agitation and delirium.
- Educate family about terminal delirium as they may interpret the manifestations of agitated delirium as pain.
- Palliate agitation and delirium aggressively as they may be particularly distressing to patients and families.

Use non-pharmacologic as well as pharmacologic measures to maximize comfort as appropriate and desired by the patient and family:

- Optimize sleep patterns.
- Maximize meaningful communication of patient with loved ones.
- Re-orient patient frequently, if possible.
- Move and turn as tolerated.
- Reduce environmental stimuli and noise.
- Incorporate individualized significant non-pharmacologic interventions into physician Comfort Care Order form.

Reassess and document symptoms following interventions:

- Standardize and document reassessment after treatment.

Know and follow best clinical practices for withdrawing life-sustaining treatments to avoid patient and family distress:

- Develop ICU protocol/guideline/pathway for the withdrawal of life-sustaining treatments, including standards for the withdrawal of ventilatory support in a manner to minimize discomfort.
- Assess in advance the family's desire to have a pastoral care representative present when life-support is withdrawn from the patient.
- Ensure the presence of the physician caring for the patient around the time life-support is withdrawn.

Eliminate unnecessary tests and procedures (lab work, weights, routine vital signs etc.), and only maintain IVs for symptom management in situations where life-support is being withdrawn:

- Develop protocol to ensure consistent implementation.

Minimize noxious stimuli (monitors, strong lights, etc.):

- Develop protocol to ensure consistent implementation.

Attend to the patient's appearance and hygiene

Ensure family and/or clinician presence so the patient is not dying alone:

- Educate staff about the importance of their presence for the support of the patient and family.

Domain 6 – Spiritual Support for Patients and Families

Assess and document spiritual needs of the patient and family on an on-going basis:

- Ask patient and/or family key spiritual assessment questions, e.g., “Are you actively involved in a spiritual/religious community? Do you want to see and talk with a pastoral care representative?”
- Document assessments.

Encourage access to spiritual resources:

- Include a “pastoral care consult assessment” category on physician Comfort Care Order form.
- Document access to spiritual resources.

Elicit and facilitate spiritual and cultural practices which the patient and family find comforting:

- When the patient is imminently dying, if spiritual issues are paramount with the patient and/or family, include the appropriate pastoral care representative who understands the patient’s and/or family’s spiritual goals or unfinished issues in clinical team discussions.

Domain 7 – Emotional and Organizational Support for ICU Clinicians

Support health care team colleagues caring for dying patients:

- Inform team members about the imminent death of a patient to increase sensitivity and awareness.
- Assist colleagues caring for dying patients by assisting in the care and/or management of that colleague's other patient care responsibilities.
- Offer colleagues a break or respite following the death of a patient they had cared for.

Adjust nursing staffing and medical rotation schedules to maximize continuity of care providers for the dying patient.

Communicate regularly with interdisciplinary team regarding goals of care:

- Develop interdisciplinary rounds.

Establish a staff support group, based on the input and needs of ICU staff and experienced group facilitators, and integrate meeting times into the routine of the ICU:

- Assist colleagues with grieving and feelings of loss after patients' deaths by formally or informally acknowledging their feelings and taking time to engage in debriefing sessions.
- Ensure that ICU staffing schedules allow for flexibility and understanding if caregivers become overwhelmed when caring for dying patients and their families.

Enlist palliative care experts, pastoral care representatives and other consultants to teach and model aspects of EOLC:

- Develop pathways to facilitate consultation with palliative care experts, pastoral care representatives and other consultants to maximize palliative care.

Facilitate rituals for the staff to mark the death of patients.