

PCCM CONFERENCE REPORT & EXPERT PANEL

Society of Critical Care Medicine 2026
Guidelines on the Care and Management of
Pediatric and Neonatal Intensive Care Patients
at the End of Life

RATIONALE: Ensuring high-quality end-of-life (EOL) care for neonatal and pediatric patients and their families in the ICU requires a comprehensive, evidence-based, multidisciplinary approach.

OBJECTIVES: To develop and provide evidence-based recommendations for EOL care and management of critically ill neonatal and pediatric patients and their families.

DESIGN: The American College of Critical Care Medicine Board convened a 21-member multidisciplinary panel of experts in pediatric critical care medicine, nursing, neonatology, psychology, spiritual care, social work, child life, respiratory care, bioethics, cardiology/cardiac intensive care, palliative care, and bereaved parents. The panel included two expert methodologists specialized in developing evidence-based recommendations in alignment with the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) methodology. Conflict-of-interest policies were followed during all phases of guidelines development including task force selection and voting.

METHODS: The panel members identified and formulated five Population, Intervention, Comparator, and Outcome questions. We conducted a systematic review of literature (2000–2025) for each question to identify best available evidence, then statistically analyzed and assessed the certainty of evidence using the GRADE methodology. We used the GRADE evidence-to-decision framework to formulate the recommendations.

RESULTS: The panel generated five conditional recommendations and one good practice statement, focused on advance care planning, pediatric palliative care consultation and education, systematic symptom management, bereavement support, and health equity in EOL care.

CONCLUSIONS: The recommendations were derived from the best available evidence at time of publication and provide valuable guidance to support EOL care for PICU and neonatal ICU patients and their families.

KEYWORDS: critical care; critical illness; end-of-life; neonatal intensive care unit; pediatric palliative care; practice guidelines

Caring for dying children is one of the most complex and consequential aspects of pediatric intensive care practice, with profound impacts on families and healthcare providers (HCPs). In the United States, studies of pediatric cohorts from the past 5–20 years continue to demonstrate that most children die in hospital, particularly in ICUs, and pediatric critical care clinicians need guidance on maximizing quality of life (QOL) and facilitating high-quality

- Sabrina Derrington¹, MD, MA,
HEC-C (Chair)^{1,2}
Elizabeth G. Broden Arciprete, PhD,
RN, CCRN, CHPPN (Vice-Chair)³
Matthew C. Lin, MD, HEC-C (Vice Chair)⁴
Simon J. W. Oczkowski, MD, MHSc,
MSc⁵
Amanda Alladin, MD, MA, HEC-C^{6,7}
Uchenna E. Anani, MD⁸
Amanda K. Borchik, MDiv, BCC^{9,10}
Cassandra A. Collins, PharmD, BCPPS¹¹
Claudia Delgado-Corcoran, MD, MPH¹²
Mindy J. Dickerman, MD¹³
Christopher G. Harrod, MS¹⁴
Natalia Henner, MD¹⁵
Alexander A. Kon, MD, HEC-C, FCCM^{16,17}
Mithya Lewis-Newby, MD, MPH¹⁸
Blyth T. Lord, MEd^{19†}
Ashley-Anne Masters, MDiv²⁰
Sarah McCarthy, PhD, MPH, ABPP^{21,22†}
Katie M. Moynihan, MBBS^{21,22}
Sara M. Munoz-Blanco, MD²³
Lauren Rissman, MD²⁴
Kathryn E. Roberts, DNP, RN, CCNS,
CENP, CCRN, FCCM¹³
Amy B. Schlegel, MD, MS²⁵
Ashleigh Schopen, MS, CCLS, FT²⁶
Linda B. Siegel, MD^{27,28}
Harriett Swasey, MSN, RN, CCRN,
C-NPT, NRP²¹
Sarah E. Wawrzynski, PhD, CCRN¹³
David J. Zorko, MD, MSc⁵
Danielle D. DeCoursey, MD, MPH
(Chair)^{21,22}

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end-of-life (EOL) care through structured and scalable interventions (1–4). We have therefore carried out systematic reviews of available literature (2000 to 2025) based on five Population, Intervention, Comparator, and Outcome (PICO) questions focused on care of pediatric patients and their families during EOL to develop evidence-based clinical practice recommendations. Pediatrics includes patients 0–21 years old as defined by the American Academy of Pediatrics (AAP). The review included the following topic areas: advance care planning (ACP), palliative care consultation, systematic symptom management, primary palliative care education, and bereavement support. EOL care issues related to ethical issues have previously been addressed in the Society of Critical Care Medicine (SCCM) guidelines and were outside of the scope of these guidelines (5). This SCCM guidelines use rigorous methodology, offering a focused evaluation of specific EOL care interventions for pediatric and neonatal patients in the ICU, including PCIU, cardiac ICU (CICU), and neonatal ICU (NICU) settings, with attention to health equity concerns, adding to EOL guidance provided by the AAP 2013–2022 (6–9), and the American Heart Association in 2023 (10). Following our comprehensive review of the available evidence, an expert panel issued five conditional recommendations and one good practice statement.

METHODOLOGY

These 2026 guidelines were developed under the auspices of the American College of Critical Care Medicine, the consultative body of SCCM, which convened a multidisciplinary panel of experts in pediatric critical care, including physicians (pediatric critical care, neonatology, cardiac intensive care, palliative care), nurses, social workers, child life specialists, psychologists, chaplains, bioethicists, pharmacists, and bereaved parents. The panel was predominantly U.S.-based, with limited representation from under-resourced and international settings. A respiratory therapist was invited to contribute to the guidelines, but scheduling conflicts limited their ability to participate. Two methodologists from the Guidelines in Intensive Care Development and Evaluation Group at McMaster University supported the process. All panel members disclosed conflicts of interest at each stage of guidelines development; none were excluded from voting. Additional details regarding methods used to develop

these guidelines are presented in the **Supplementary Materials** (see **Sections 1** and **2**, <https://links.lww.com/PCC/C707>).

The panel conducted systematic reviews of the 2000–2025 literature to answer each of five PICO questions related to EOL care for infants and children in ICU settings (Supplementary Materials, **Sections 2** and **3**, <https://links.lww.com/PCC/C707>). The guidelines were limited to five PICO questions per SCCM's standard operating procedures for guidelines development. The systematic reviews were not registered. The panel rated the relative importance of potential outcomes to prioritize those that were critical for decision-making. PICO questions and outcomes are listed in **Table 1** and described further in the Supplementary Materials (**Sections 4** and **5**, <https://links.lww.com/PCC/C707>). A medical librarian performed initial searches in MEDLINE, Embase, Cochrane Clinical Trials Register, and CINAHL through May 2024. Additional studies were identified through review of reference lists of included studies and expert suggestion. Search details, including a Preferred Reporting Items for Systematic reviews and Meta-Analyses flow diagram (**Supplementary Fig. S1**, <https://links.lww.com/PCC/C707>).

Screening, full-text review, data extraction, and risk of bias assessment were conducted using Covidence (Veritas Health Innovation, Melbourne, VIC, Australia) (11). Risk of bias for randomized controlled trials (RCTs) was assessed using the modified Cochrane Risk of Bias tool (the Cochrane Collaboration, London, United Kingdom) (12). Where possible, outcomes were meta-analyzed using Dataparty (Dataparty Midt-Norge Ans, Spillum, Norway) (13). Outcomes not amenable to meta-analysis were synthesized narratively, including qualitative data. Evidence summaries and data tables are included in the Supplementary Materials (Section 5, <https://links.lww.com/PCC/C707>).

Clinical practice recommendations and the good practice statement were developed using the Grading of Recommendations, Assessment, Development, and Evaluation framework (14, 15). For each PICO question, the panel completed Evidence-to-Decision frameworks using GRADEPro (Evidence Prime, Hamilton, ON, Canada) (16), evaluating the balance of benefits and harms, certainty of evidence, resource use, feasibility, acceptability, and equity. Recommendations required 17 or more of the 21-member panel (i.e., $\geq 80\%$) to agree, before the recommendation was approved.

TABLE 1.
Population, Intervention, Comparator, and Outcome Questions

In these two populations:		
1) Parents of infants and children (prenatal or older) who die during or following a stay in the PICU, cardiac ICU, or NICU		
2) Neonatal and pediatric patients with life-threatening or life-limiting illness who receive care in an ICU before death		
PICO 1: For pediatric patients and parents of infants and children with life-threatening or life-limiting illness, do advance care planning conversations with clinicians improve EOL care?		
Intervention	Comparator	Outcomes
Advance care planning discussion, with any clinical team member at any time	No advance care planning or goals-of-care discussions	Satisfaction with EOL symptom management for patients Satisfaction with goals-of-care communication, decision-making Parent/caregiver experience Intensity of care/healthcare utilization at EOL and alignment of care plan with patient/caregiver goals Quantity/quality of goals-of-care conversations Completion of patient-/family-desired bereavement/grief support interventions
PICO 2: For pediatric patients and parents of infants and children with life-threatening or life-limiting illness, does palliative care team consultation/collaboration in PICU and NICU, compared with no palliative care consultation or usual care, improve EOL care?		
Intervention	Comparator	Outcomes
Specialty palliative care consultation (any model of palliative care consultation)	No specialty palliative care consultation	Satisfaction with EOL symptom management Satisfaction with goals-of-care communication, decision-making Parent/caregiver experience Healthcare provider/staff coping/resilience, moral distress and burnout, satisfaction, and confidence in providing EOL care Intensity of care/healthcare utilization at EOL Quantity/quality of goals-of-care conversations
PICO 3: For children and infants admitted to PICU or NICU with life-threatening or life-limiting illness, does the use of a systematic, patient-centered symptom assessment/management plan, compared with usual care, improve patient symptoms, family satisfaction with care, and family mental health symptoms?		
Intervention	Comparator	Outcomes
Systematic (not necessarily protocolized but based on best practice/evidence-based) patient-centered approaches to symptom assessment or management and withdrawal of life-sustaining therapy	Usual care	Satisfaction with EOL symptom management Parent/caregiver experience Healthcare provider/staff coping/resilience, moral distress and burnout, satisfaction, and confidence in providing EOL care Satisfaction with overall ICU and EOL care
PICO 4: For staff working in PICU and NICU, do education programs in palliative care skills (including symptom management, communication, psychosocial, and spiritual care), compared with no such education, improve patient and family satisfaction with care, symptom management, rates of conflict, staff mental health symptoms, staff burnout symptoms, and self-efficacy for EOL care?		
Intervention	Comparator	Outcomes

(Continued)

TABLE 1. (Continued)
Population, Intervention, Comparator, and Outcome Questions

Education programs (any kind—including seminars, simulation) in palliative care skills (including symptom management, communication, psychosocial, and spiritual care)	No education program in palliative care skills	Satisfaction with EOL symptom management Satisfaction with goals-of-care communication, decision-making Parent/caregiver experience Healthcare provider/staff coping/resilience, moral distress and burnout, satisfaction, and confidence in providing EOL care Patient/family healthcare team conflict Satisfaction with overall ICU and EOL care
PICO 5: For children and infants admitted to a PICU or NICU with life-threatening or life-limiting illness, does the use of bereavement/grief support programs/interventions during or after ICU stay (including memory/legacy making interventions) improve family satisfaction with care and family mental health outcomes?		
Intervention	Comparator	Outcomes
Bereavement/grief support programs/interventions during or after ICU stay (including memory/legacy making interventions, bereavement/grief support follow-up)	Usual care	Satisfaction with overall ICU and EOL care Parent/caregiver symptoms Parent/caregiver preparedness at child's EOL Involvement of psychosocial support

EOL = end-of-life, NICU = neonatal ICU, PICO = Population, Intervention, Comparator, and Outcome.

Before publication, the literature search and evidence summaries were updated. These guidelines therefore reflect the best available evidence through November 2025.

A task force comprised of volunteer members from this writing panel developed an implementation toolkit including a blueprint with tools designed to help ICU leaders assess needs, identify barriers, and effectively implement the recommendations in their local environments. The toolkit provides guidance for tailoring implementation across settings with variable resources and includes educational materials for clinicians and patients/families. This toolkit is provided on the SCCM guidelines webpage (<https://www.sccm.org/clinical-resources/guidelines>).

RECOMMENDATIONS

The recommendations in these guidelines outline principles of practice intended to guide care for most pediatric patients and families navigating EOL in an ICU setting, including PICU, CICU, and NICU. We recognize that EOL care needs and experiences of children may vary based on age, setting, and developmental level and focus our recommendations on components of care that are applicable across these factors. When appropriate, accompanying remarks offer guidance

for clinical implementation, including when practices are recommended for all settings vs. more aspirational goals for well-resourced settings (see additional Implementation Toolkit). Each recommendation was assigned a strength (“Strong” or “Conditional”), based on the quality of available evidence. Strong recommendations should be applied in nearly all cases and may serve as the basis for quality measures. Conditional recommendations reflect uncertainty or variability in how individuals may value the effects of an intervention, which may arise from variation in feasibility, acceptability, costs, or uncertainty in effects. These recommendations should be implemented using shared decision-making, with careful consideration of patient and family values, preferences, specific clinical context and evolving research. The recommendations are summarized in **Table 2** with supporting evidence for each outcome described below.

ADVANCE CARE PLANNING

Recommendation 1: We suggest implementing an ACP process for pediatric patients and parents of infants and children with life-threatening or life-limiting illness (Conditional recommendation for, very low certainty evidence).

TABLE 2.
Recommendations and Good Practice Statement

Recommendation No.	Recommendation	Strength of Recommendation
1	We suggest implementing an advance care planning process for pediatric patients and parents of infants and children with life-threatening or life-limiting illness	Conditional recommendation for, very low certainty evidence
2	We suggest pediatric palliative care consultation for children and infants with life-limiting or life-threatening illness	Conditional recommendation for, very low certainty evidence
3	We suggest using a systematic approach to symptom assessment and management to meet patient and family goals for EOL care vs. an ad hoc approach to symptom management	Conditional recommendation for, very low certainty evidence
4	We suggest palliative care education for staff caring for children and infants with life-limiting or life-threatening illness	Conditional recommendation for, very low certainty evidence
5	We suggest implementing a bereavement care process for children/infants and their families/caregivers during or after death	Conditional recommendation for, very low certainty evidence
	Pediatric and neonatal clinicians should actively address disparities in pediatric EOL care by eliminating barriers to high-quality palliative care for all patients and families with particular attention to communities and/or populations that have been marginalized based on race, ethnicity, preferred language, country of origin, gender identity, sexual orientation, religious and spiritual identity, etc. through: 1) recognition and mitigation of personal biases with an attitude of cultural humility, 2) identifying and addressing structural racism and institutionalized discrimination, and 3) engagement of patient, family, and community perspectives and experiences in the care process	Good practice statement

EOL = end-of-life.

Rationale: Pediatric ACP is defined as a process that supports surrogate decision-makers and, when developmentally appropriate, pediatric patients with serious illness in sharing their goals, values, and preferences to ensure that future medical care is goal-concordant (9, 17). ACP is often a longitudinal, iterative and dynamic process requiring multiple conversations and skilled communication.

Patient Symptoms

The evidence is uncertain on the effect of ACP on patient mental health symptoms and QOL in pediatrics. In the one available RCT from 2010 to 2012 (18), adolescent/young adult (AYA) patients with cancer who underwent ACP outside of the ICU had little to no difference in anxiety and depression symptoms (mean difference [MD], -1.4 points [95% CI, -3.43 to 0.63]

and -1.1 points [95% CI, -4.54 to 2.34], respectively) based on the Beck anxiety and depression scale. The patients' QOL ratings with ACP based on the pediatric QOL inventory showed MD 1.0 point (95% CI, -7.52 to 9.52). All these differences are imprecise, with wide CIs and small sample sizes.

Parent Satisfaction With Symptom Management for Patients

Narrative synthesis of three nonrandomized studies provided low certainty evidence suggesting ACP may improve satisfaction with EOL symptom management for patients. In a survey of bereaved parents, ACP was associated with lower odds of perceived patient suffering (adjusted odds ratio [OR], 0.52 [95% CI, 0.18–1.48]), and higher odds of perceived patient QOL (adjusted OR, 3.59 [95% CI, 1.23–10.37]) (19).

In a retrospective survey of bereaved parents of infants who died in a NICU, parents who reported participating in ACP rated their infants as having less pain and fewer breathing difficulties (20). In a cross-sectional survey and chart review, higher parent-rated preparedness was associated with less perceived suffering for their child (21).

Communication and Decision-Making

The evidence is uncertain on the effect of ACP on communication and decision-making. Another analysis of the RCT described above (18) demonstrated that ACP may result in little to no difference in communication quality in pre-ICU AYAs with cancer based on the quality of communication (QOC) score (MD, 1.0 point [95% CI, -0.01 to 2.01]) (22). Additional data from a single-group pilot study to determine the feasibility and acceptability of the Pediatric Serious Illness Communication Program (2021–2023) (23) similarly demonstrated ACP may result in little to no difference in the QOC score with ACP for PICU patients (MD, 0.0 points [95% CI, -0.8 to 0.8]). Narrative synthesis of three nonrandomized studies provides low certainty evidence suggesting ACP may result in increased satisfaction with decision-making. In a survey of bereaved parents of children and AYAs with complex chronic conditions, ACP was associated with lower odds of decisional regret (adjusted OR, 0.52 [95% CI, 0.19–1.41]) (19). In a pilot study of an ACP intervention for parents of children with serious illness, therapeutic alliance, as measured by the Human Connection Score (HCS), increased after ACP (mean [SD] HCS 57.6 [6.4] from HCS 55.3 [7.8]) and anxiety based on the Generalized Anxiety Disorder-7 decreased (mean [SD] 8.4 [6.9] from 10.1 [7.3]), with no differences in shared decision-making (23). In a retrospective survey of bereaved parents of infants who died in the NICU, parents who had ACP discussions were more likely to report that the medical team had listened to their concerns, that they received consistent information, that team members were working toward the same goal, and reported higher levels of shared decision-making regarding withholding life-sustaining treatments for their children (24).

Family/Caregiver Experience

The evidence is very uncertain about the effect of ACP on the family/caregiver experience. One RCT, already

cited (18) demonstrated little to no difference in family anxiety and depression with ACP for pre-ICU patients based on the Beck anxiety and depression inventories (MD, 0.5 points [95% CI, -4.81 to 5.81] and MD, 0.0 points [95% CI, -5.68 to 5.68], respectively). Evidence from two RCTs demonstrated ACP may improve family coping for both pre-ICU adolescents (25) and infants undergoing surgery for single ventricle congenital heart disease (26) based on the caregiver strain score (MD, -0.24 points [95% CI, -0.58 to 0.1] and the brief cope inventory MD, -0.7 points [95% CI, -1.41 to 0.01], respectively). An analysis of the same two RCTs (25, 26) demonstrated no improvement in family QOL with ACP for these patient groups, based on the family well-being score (MD, -0.86 points [95% CI, -1.13 to -0.59]) and the Pediatric Quality of Life Inventory Family Impact Module (MD, -0.2 points [95% CI, -11.97 to 11.57]). A narrative synthesis of three non-randomized studies demonstrated ACP may improve parental experience at EOL. A survey of bereaved parents of children with complex chronic conditions showed ACP was associated greater odds of parental preparedness for a child's death (adjusted OR, 3.78 [95% CI, 1.33–10.77]) (19). A cross-sectional survey and chart review of children with complex chronic conditions reported higher parent-rated preparedness was associated with lower odds of perceived child suffering (adjusted OR, 0.20 [95% CI, 0.07–0.60]) (21). In a qualitative study of eight bereaved parents whose children died in NICU, parents had different levels of comfort (i.e., very comfortable to uncomfortable) when participating in ACP discussions (27). In a qualitative study of bereaved parents whose children died in PICU, parents reported that ACP can be emotionally overwhelming but is possible once parents reach a place of acceptance about their child's EOL (28).

Intensity of Care at End of Life

Studies evaluating the effect of ACP on the intensity of care at EOL yielded very uncertain evidence due to imprecision and indirectness in outcome measurement. One RCT (26) suggests a possible reduction in duration of mechanical ventilation in infants prenatally diagnosed with single-ventricle heart disease who received ACP communication (MD, -3.0 d [95% CI, -7.43 to 1.43 d]). However, findings evaluating ICU length of stay in pediatric and neonatal intensive care patients with ACP were inconsistent across one RCT

(26) and two observational studies (20, 29), likely reflecting differences in patient populations (general NICU vs. CICU patients with single ventricle cardiac disease). In a cross-sectional survey and retrospective chart review of bereaved parents of children with complex chronic conditions (19), out of 40 of 147 parents who responded to the survey, those reporting ACP had greater odds of being prepared for their child's EOL (adjusted OR, 3.78 [95% CI, 1.33–10.77]), to have greater odds of planning their child's location of death (adjusted OR, 2.93 [95% CI, 1.06–8.07]), and greater odds of rating their child's QOL at EOL as good to excellent (adjusted OR, 3.59 [95% CI, 1.23–10.37]). They were also less likely to receive intensive life-sustaining measures in their last 2 days of life (12/66 vs. 15/36; $p = 0.01$) and more likely to have palliative care involvement (65/69 vs. 18/36; $p < 0.01$) (19). In two retrospective cohort studies, earlier (i.e., > 48 hr before death) do-not-resuscitate (DNR) orders were associated with fewer invasive procedures (0.68/d) compared with late (2.0/d) or no DNR orders (2.09/d) (30). In the other study (31), out of 62 patients who died at a single center in Australia, in 2011, 23 died (37%) at home and 16 died (26%) in the PICU or high-dependency unit (HDU): of note, all deaths in the PICU/HDU had a resuscitation plan, whereas only 15 of the deaths at home had a resuscitation plan. Similarly, a retrospective cohort study across three hospitals showed AYAs with cancer who engaged in earlier ACP discussions (> 30 d before death) had lower rates of chemotherapy ($p = 0.001$), ICU care ($p < 0.001$), emergency room visits ($p < 0.001$), or hospitalizations ($p < 0.001$) (32). Finally, an observational study evaluating the impact of weekly goals-of-care meetings for long stay PICU patients (60 patients in the interventional arm and 66 historical controls) found parents in the intervention group more often made decisions to withhold or withdraw treatments (28% vs. 11%; $p = 0.013$) without differences in long-term mortality, with higher in-hospital mortality (25% vs. 9%; $p = 0.015$) and shorter PICU length of stay (3.4 vs. 4.9; $p = 0.015$) (33).

Goals-of-Care Documentation

Evidence from two RCTs evaluating AYAs with cancer (34, 35) demonstrated that advance directives, treatment limitation orders, and DNR orders had greater odds of occurring in patients with pre-PICU ACP (risk ratio, 1.53 [95% CI, 0.17–13.88]). Additional data from

four nonrandomized studies of ACP within the PICU and NICU (19, 32, 33, 36) demonstrated that advance directives, treatment limitation orders, and DNR orders had greater odds of occurring in patients with ACP (OR, 2.36 [95% CI, 1.2–4.63]). This evidence is, again, uncertain.

Summary

The overall certainty of the evidence regarding the effects of ACP on selected outcomes was very low due to risks of selection bias, imprecision, and inconsistency, resulting in a conditional recommendation. An ACP process should include a structured approach to eliciting hopes, worries, goals, and preferences for medical care from the parents and, when developmentally appropriate, the patient, tailoring clinical recommendations and care plans to align with those goals (17). While this process may require adaptation depending on patient, family, and situational factors, the core components remain the same across PICU, CICU, and NICU settings. ACP may be facilitated by any health-care professional who cares for children with serious illness, including intensive care clinicians. Subspecialty palliative care clinicians have particular expertise in ACP but are not readily available in all practice settings and cannot be present for every critical moment or decision in an ICU. Regardless of whether ACP has been initiated before ICU admission by clinicians with longstanding relationships with the patient and family, pediatric and neonatal critical care clinicians are often called upon to initiate and lead these conversations in critical care settings. ACP is often a continuum that may stretch across outpatient, inpatient, intensive care, and transitional care settings. There is limited evidence suggesting ACP may have moderate desirable effects on parental satisfaction with EOL symptom management, communication, and decision-making; patient-caregiver experience; and goals-of-care conversations and documentation. The variable effects of ACP on intensity of EOL care may reflect variation in patient/family needs and goals. Importantly, we did not find any studies that described the impact of ACP on goal-concordant care, a high-priority outcome in ACP research (37). Possible negative effects of ACP may include patient, parent, and clinician discomfort with discussing preferences for care at EOL. However, existing evidence does not demonstrate that ACP discussions independently cause harm. Emotional distress

observed in the context of these conversations is often confounded by the underlying seriousness of the child's condition and proximity to EOL, making it difficult to isolate the specific contribution of ACP to overall distress. Patients and families may simultaneously experience some degree of expected distress from ACP but may also find it beneficial when conducted in a sensitive and timely manner by skilled clinicians.

There is little data on costs or cost-effectiveness, and while ACP requires clinician time and effort, it may also reduce costs if patients/families forego costly treatments and future intensive care. Cost and effort may reflect the complexity of the ACP intervention in question (i.e., use of a standardized communication guide alone vs. a larger program that educates clinicians on how to use the guide with a corresponding electronic medical record tool), many of which varied across studies. Because ACP is intrinsically concerned with exploring patients' and families' experiences with illness, it may increase healthcare equity by creating opportunities for clinicians to proactively identify and mitigate barriers to goal-concordant care, particularly barriers related to racism and other forms of discrimination. Of note, increasing opportunities for ACP does not in itself ensure more equitable ACP; to be effective, ACP should be provided in a manner sensitive to the patient and family needs (i.e., language, cultural, spiritual), with recognition that EOL care preferences likely vary between individuals. Lastly, the panel judged that ACP would likely be acceptable to patients and families and feasible to implement in most clinical practice settings as a core practice (see Implementation Toolkit: available online at <https://www.sccm.org/clinical-resources/guidelines>).

PALLIATIVE CARE TEAM CONSULTATION AND COLLABORATION

Recommendation 2: We suggest pediatric palliative care (PPC) consultation for children and infants with life-limiting or life-threatening illness (Conditional recommendation for, very low certainty evidence).

Remarks: While most patients and families may benefit from PPC, in some cases, it may be necessary and appropriate for palliative care to be provided by the ICU team. ICU and PPC teams should collaborate to balance consultation practices with the development of primary PPC skills, considering local resources and

the individualized needs and preferences of patients and families.

Rationale

Quality of Dying and Death. An analysis of one non-randomized study (38) of family members of pediatric patients receiving intensive care demonstrated very low certainty evidence that PPC may result in little to no difference in Quality of Dying and Death (QODD) scores (MD, 0.2 points [95% CI, -1.32 to 1.72]) compared with no PPC.

Patient Symptoms. A meta-analysis of two nonrandomized studies (39, 40) demonstrated that infants who received PPC may experience more symptoms than infants who did not receive PPC (MD, 1.21 symptoms [95% CI, 0.92–1.51]), but the evidence is very uncertain, likely due to selection bias (children with more symptoms may be more likely to receive PPC).

Documented Goals-of-Care Conversations. The pooled estimate across ten nonrandomized studies (39–48) demonstrated very low certainty evidence of higher odds of documentation of care goals among patients who receive PPC (OR, 5.1 [95% CI, 2.48–10.49]).

Treatment Limitation Orders. Analysis of 17 non-randomized studies (39–44, 48–57) demonstrated very low certainty evidence of greater odds of more treatment limitation orders among patients who received PPC compared with no PPC (OR, 5.73 [95% CI, 3.74–8.79]).

Length of Stay. A meta-analysis of 12 nonrandomized studies (40, 43, 45, 51, 53–56, 58–61) demonstrated an association with PPC and increased mean length of stay in critical care (MD, 7.78 d [95% CI, 2.17–13.4 d]). A meta-analysis of 8 nonrandomized studies (51, 53, 54, 58, 59, 62–64) demonstrated an association with PPC and an increase in mean hospital length of stay (MD, 25.32 d [95% CI, 6.72–43.91 d]). The evidence is very uncertain for both these outcomes.

Hospital Admission Costs Before Death. Analysis of two nonrandomized studies (43, 62) generated very uncertain evidence for an association between PPC and increased mean hospital admission costs before death (MD, \$60,196 [95% CI, -120,115 to 240,508]) compared with no PPC.

Involvement of Supportive Care Services. The pooled estimate across four nonrandomized studies (40, 41, 45, 55) comparing PPC to no PPC,

demonstrated very low certainty evidence of higher odds of involvement of psychosocial and spiritual supportive services with PPC, for example, referral to social work, bereavement counseling, memory making, and chaplaincy (OR, 3.62 [95% CI, 1.75–7.52]).

Summary. The overall certainty of the evidence for PPC consultation was very low due to risk of bias, and inconsistency and imprecision in outcomes. We considered subspecialty PPC to include any palliative care services (i.e., supporting ACP and shared decision-making, improving QOL, providing relief from physical, emotional, psychological, and spiritual suffering) delivered by specialized palliative care teams at any stage of a child's serious illness trajectory. Early integration of PPC teams at or around the time of a life-limiting diagnosis establishes a relationship that allows for longitudinal support that can evolve over time to meet the needs of dynamic goals and disease progression. Most studies were observational and often cross-sectional; thus, we could not draw definitive conclusions about direction of associations for both desirable and undesirable effects. Study outcomes focused heavily on care utilization measures (i.e., length of stay, intensity of care), which must be contextualized within patient and parent goals. Although symptom burden appeared to be higher in some studies in children with PPC, this is not likely causal and may reflect the greater complexity of patients referred for subspecialty PPC. Despite these findings, qualitative research including both parent and healthcare team perspectives described the immense value of PPC, including supporting continuity, improving communication, and providing emotional support for families through their child's illness trajectory. The panel judged that the required resources for PPC vary substantially by center depending upon staffing and care delivery models (65–67). Cost comparisons should be interpreted carefully, considering the higher complexity of patients who require palliative care. For this population, there may be cost-saving effects with PPC, with fewer invasive treatments used as reported in studies, despite longer length of stay. The panel was uncertain about the impact of PPC on health equity, as existing disparities in the access to and delivery of PPC for racially and ethnically minoritized patients may limit potential benefits (68, 69). The panel judged that PPC would probably be acceptable to implement, but feasibility, extent, and sustainability of services may vary due to differences in institutional palliative care resources.

SYSTEMATIC SYMPTOM ASSESSMENT/MANAGEMENT PLAN

Recommendation 3: We suggest using a systematic approach to symptom assessment and management to meet patient and family goals for EOL care vs. ad hoc approach to symptom management (Conditional recommendation for, very low certainty).

Remarks: A systematic approach to symptom management includes assessment of physical and psychological symptoms, treatment of symptoms, and provision of relevant family support (e.g., education, spiritual care, family presence).

Rationale

Symptom Management Quality and Satisfaction.

A narrative synthesis of five nonrandomized studies demonstrated very low certainty evidence for the impact of a systematic symptom management approach on satisfaction and quality of EOL symptom management. A survey of 205 NICU staff published in 2023 and carried out before and after implementation of an EOL guideline (70) found that most PICU-QODD-20 scores either stayed consistent or improved across all domains. Neonatal Pain, Agitation, and Sedation Scale scores in the 24 hours before death were similar. In an older, retrospective pre- vs. post-implementation of a palliative care plan, carried out 2008–2013 (71), 44 infants before were compared with 22 infants after the implementation. The authors found a greater proportion of infants received palliative medications post-intervention vs. pre-intervention (14/22 vs. 16/44; MD, 28% [95% CI, 2.6–48.7]; $p = .003$). There is another pre- (2003–2005) vs. post-study (72). Here, an implementation of palliative care order set was introduced in 2007, and the authors compared deaths in 2003–2005 (82 infants pre) vs. 2008–2009 (68 infants post) and found similar morphine use but increased benzodiazepine use after implementation. Similarly, Lofgren et al (73) conducted a quality improvement project to implement EOL guidelines in the PICU, finding an increased use of mean fentanyl units used during the last 24 hours (17.1 vs. 70.1 mcg/kg). Rinaldi et al (74) found the implementation of a compassionate extubation guideline resulted in increased use of appropriate extubation orders.

Parent/Caregiver Experience. Available evidence regarding the impact of systematic symptom

management on caregiver experience was limited to one nonrandomized study. A study of 344 infant deaths, 2009–2019 (75), occurring before and after implementation of a NICU palliative care protocol found that implementation the protocol was associated with increased use of photography (92% vs. 75%), death in a private room (49% vs. 15%), and parental presence at death (98% vs. 91%). Analgesia use or offering of baptism or rituals was unchanged.

Healthcare Staff Satisfaction. A single nonrandomized study surveying 205 NICU staff before and after implementation of an EOL guideline found that staff satisfaction with education related to EOL care for infants improved post-guideline, providing the only available data on the impact of systematic symptom management on HCP satisfaction (70).

Summary. The certainty of evidence for the outcomes was very low due to indirect evidence of quality of symptom management, and parent/caregiver satisfaction and mental health symptoms. Most published research was observational and descriptive without a specific intervention, and there was very limited data in PICU or CICU populations for the panel to review. In the interventional studies, many protocols were evaluated using medication administration data, which may not fully reflect the patient or family's symptom experience. The panel judged that the balance between the desirable and undesirable effects favors the use of a systematic approach to symptom assessment and management, which could improve the consistency and comprehensiveness of symptom evaluation and management over an ad hoc approach. Since 10–20 years old cohorts show us that most deaths in the PICU and NICU followed a planned limitation or withdrawal of life-sustaining treatments (1, 2), a contemporary systematic, comprehensive approach and reevaluation could help clinicians identify and meet patient and family physical and psychosocial needs in 2026 onward. However, given variability in EOL care preferences, any protocol should be tailored to align with patient/family preference, as well as patient age and developmental level. For example, some families may prioritize spending time with their child awake, tolerating some degree of discomfort; other families may perceive any discomfort/distress as unacceptable and may request higher levels of sedation. The use of systematic protocols likely results in increased health equity by providing consistent care and decreasing the

likelihood of undetected or undertreated symptoms, of particular risk for infants and nonverbal or neurologically impaired children who have difficulty expressing symptoms. The panel also judged that a systematic approach to symptom assessment and management would likely be acceptable to key stakeholders and feasible to implement as a core practice in most settings.

EDUCATIONAL PROGRAMS IN PRIMARY PALLIATIVE CARE SKILLS

Recommendation 4: We suggest palliative care education for staff caring for children and infants with life-limiting or life-threatening illness (Conditional recommendation for, very low certainty evidence).

Rationale

Healthcare Provider Self-Efficacy and Confidence in Palliative Care. A meta-analysis of ten nonrandomized studies (76–85) demonstrated very low certainty evidence that palliative care education may increase HCP self-efficacy (standardized mean difference [SMD], 1.47 [95% CI, 0.74–2.2]). Studies often compared their education intervention to no specific education, and self-efficacy was heterogeneously measured and considered, but was not limited to communication, pain and symptom management, overall knowledge of palliative, and/or EOL care. Ten additional studies (73, 86–94) reported increases in HCP confidence with EOL care after implementation of an education program.

Healthcare Provider Satisfaction With Symptom Management. The evidence from three nonrandomized studies is very uncertain about the effect of palliative care education on satisfaction with symptom management. Two studies already discussed (71, 72) reported an increased use of comfort medications after implementation of an HCP education program. Another educational study, assessing performance in managing pain after introduction of a curriculum in 2009–2010 for pediatric residents (79) reported no difference in third-party adjudication of pain management.

Healthcare Provider Satisfaction With Communication. Narrative synthesis of five nonrandomized studies generated very low certainty evidence for the impact of palliative care education on HCP satisfaction with communication. Three studies reported

no improvement in communication outcomes after implementation of an HCP education program (71, 79, 89). A study from Taiwan, approved in 2016 (78), reported increases in confidence, communication competence, performance, and satisfaction in NICU nurses after implementation of case-based simulation or didactic lectures on palliative care communication. The final study from the United States (2025) reported increases in comfort in communicating about impending death by NICU nurses after implementation of local EOL guidelines, which included multidisciplinary staff education (73).

Healthcare Provider Mental Health Symptoms, Grief, and Team Conflict. Three nonrandomized studies were narratively synthesized, providing very low certainty evidence for the impact of education on HCP mental health symptoms or moral distress, with effects including decreased anxiety around pediatric EOL care (92) and no change in attitudes related to coping with EOL care (76, 86). One nonrandomized study in NICU providers, which was published in 2021 (76), examined the relationship between weekly NICU case-based discussions and team practices. The authors reported no change in between staff issues and team conflict related to palliative care issues after implementing the case-discussion program.

Healthcare Provider Satisfaction With EOL Care. A narrative synthesis of two nonrandomized studies generated very uncertain evidence for the effect of palliative care education on satisfaction for overall ICU or EOL care. The study mentioned above, about the NICU provider case-based discussions (76), also found an increase in HCP satisfaction with institutional execution of EOL care. Last, an observational study of EOL “empathy workshops” developed in 2015 and studied in 2016–2018 at a single center (94), identified multiple improvements in NICU parent experience.

Summary. Primary palliative care is defined as basic palliative care principles incorporated by primary teams, such as intensive care clinicians (95). Training ICU clinicians in primary palliative care skills may improve communication, pain and symptom management, ethical decision-making, family support, personal/professional conflicts in EOL care, and compassion fatigue. The overall certainty of this evidence was very low due to several factors, including risk of bias, indirectness of the interventions (e.g., studies evaluating outcomes after educational interventions

rather than in actual clinical practice), nonstandardized outcome measurements, and imprecision. There are likely net desirable benefits to palliative care education, particularly around HCP self-efficacy in providing palliative and EOL care, and the undesirable effects are likely minimal. Required resources to implement educational interventions likely vary depending on course content, delivery style, frequency, and duration. The panel was uncertain about the impact on health equity as there was no explicit evaluation reported in the literature. Some educational interventions integrated cultural and religious content into programming, but the impact of this content on equity is unclear. Based on participant evaluations reported in many of the studies, the panel judged that educational interventions are probably acceptable to key invested parties but feasibility to implement them may vary depending on the model used and institutional support, resulting in a conditional recommendation whose implementation may depend on high resource availability.

BEREAVEMENT SUPPORT PROGRAMS AND INTERVENTIONS

Recommendation 5: We suggest implementing a bereavement care process for children/infants and their families/caregivers during or after death (Conditional recommendation for, very low certainty evidence).

Remarks: A bereavement care process is a structured approach to supporting families and caregivers before, during, and after the death of a child.

Rationale

Satisfaction With Care. A meta-analysis of two nonrandomized studies (96, 97) demonstrated little to no effect on satisfaction with care (SMD, 0.6 SDs higher; 95% CI, 0.34 lower to 1.55 higher), but the evidence is very uncertain. Bereavement support consisted of debriefing sessions for parents (96), and a combination of facilitated bonding time with the child, creation of legacy items, and dedicated interviews with psychology for emotional support (97) for these studies.

Caregiver Mental Health. One RCT (98) demonstrated little to no effect on caregiver depression with video bereavement education for parents compared with no bereavement support based on one or more of the following measures: Edinburgh Postnatal

Depression Scale, Hamilton Depression Rating Scale, and Center for Epidemiologic Studies Depression questionnaire but the evidence is very uncertain. A narrative synthesis of three RCTs (98–100) demonstrated very uncertain evidence about the effect of bereavement interventions on caregiver grief assessed by various scales. One nonrandomized study (97) reported similar findings.

Social Support. An analysis of one RCT (98) demonstrated little to no change in social supportedness with video bereavement education for parents compared with no bereavement support (MD, 1.3 points [95% CI, –4.17 to 6.77]), based on the 24-item Social Provisions Scale.

Summary. The overall certainty of the evidence for implementing a bereavement care process for children/infants and their families during or after death was very low due to imprecision, inconsistency, and risk of bias. Bereavement care refers broadly to services aimed at helping caregivers/parents and siblings cope with the death of a child and services can include emotional, informational, and practical assistance such as peer-support, counseling, memorial services, memory-making activities, and referrals to other resources. Services should be tailored to the unique needs and preferences of each family, with sensitivity to cultural and individual differences, child age, and developmental level. Considerable qualitative data supports the delivery of bereavement care, highlighting its desirable effects and the significance of these effects (101–105). However, certain aspects of interventions (e.g., returning to the hospital for bereavement care or follow-up) may be distressing for some families—although this may vary as distress is context-dependent (104, 106). Other interventions offer families opportunities to access resources on their own time and from their own home after a child's death, such as the self-guided bereavement video by Rosenbaum et al (98), which contains interviews with other bereaved parents and psychosocial experts. There is variability and nuance to initiating and delivering bereavement care, which must be individualized and involves respecting and incorporating families/caregivers' unique values, preferences, cultural practices, and spiritual beliefs. Giving families/caregivers choice and control over bereavement care options can promote equity, especially considering EOL is a time and environment where they may experience little control

or opportunity to personalize their experience. When these equity aspects are thoughtfully addressed, sensitive bereavement care will probably promote health equity. A lack of sensitivity to these individualized needs can have unanticipated consequences such as retraumatization of loss or lack of support. However, when implemented sensitively, the undesirable effects are likely minimal. Qualitative data from bereaved parents of infants and children suggest that families/caregivers often want to participate in bereavement care interventions but have difficulty initiating meaningful interventions without the guidance of HCPs (106, 107). Considering this, there is probably no important variability in how much families value the main outcomes of interest. Therefore, the panel concluded that the balance between desirable and undesirable effects supported a conditional recommendation for the use of bereavement care in clinical practice.

The timing of initiating bereavement care processes varies—it may begin before the child's death, and span the EOL period, immediate dying phase, and follow-up after death. This care is not limited to that provided in the hospital and can include a range of interventions, from one-time low-cost supports (e.g., memory making activity) to more intensive, resource-dependent services involving dedicated mental health professionals.

HCPs and families/caregivers view bereavement care to be acceptable and an important component of EOL care. However, since there is no standard for bereavement care, a wide range of interventions exist. The feasibility and sustainability of implementation depend on the capacity and resources of individual healthcare systems and families/caregivers' preferences. Offering the bereavement support available within an individual health system should be considered a core practice in EOL care in pediatric and neonatal intensive care settings.

Good Practice Statement: Pediatric and neonatal clinicians should actively address disparities in pediatric EOL care by eliminating barriers to high-quality palliative care for all patients and families with particular attention to communities and/or populations that have been marginalized based on race, ethnicity, preferred language, country of origin, gender identity, sexual orientation, religious and spiritual identity, etc. through: 1) recognition and mitigation of personal biases with an attitude

TABLE 3.
Research Priorities

Topic	Research Priorities
Advance care planning conversations	Develop and validate clinically meaningful patient and parent/caregiver outcome measures, in particular goal-concordant care, for studies of ACP and EOL in pediatric and neonatal critical care settings Determine the impact of ACP on staff outcomes (e.g., moral distress, burnout, job satisfaction and attrition) Determine the effectiveness of different ACP approaches related to the timing/setting, type of intervention (e.g., conversation guide, documentation activity, patient/parent/staff education), follow-up, and evaluation Evaluate patient and parent/caregiver preferences around the provision of ACP Evaluate interventions to overcome barriers and the effects of these interventions on patient, family, and clinician outcomes Characterize drivers of inequitable access and delivery of ACP with potential solutions Examine optimal timing and developmental adaptation of ACP conversations across pediatric age groups Evaluate effectiveness of culturally and linguistically tailored ACP materials and processes
Pediatric palliative care team consultation and collaboration	Evaluate processes for timely and appropriate consultation and integration of PPC for children with life-threatening or life-limiting illness Identify models of specialty and primary palliative care that may fit the needs of institutions with a variety of resource capabilities Characterize drivers of inequitable access and delivery of PPC consultation with potential solutions Conduct more causal studies (whether using historical data/controls or RCTs) to assess impact of palliative care Assess implementation outcomes (feasibility, fidelity, sustainability) of PPC consultation models across diverse ICU settings Explore family perspectives on PPC team involvement across illness trajectories and points of care
Systematic patient-centered symptom assessment/management planning	Standardize approaches to symptom management and other supportive care for patients and families at EOL in pediatric and neonatal critical care Define optimal assessment and treatment strategies for symptoms at EOL to address evidence of variations in care in medications and doses used Develop processes to elicit patient/family goals for EOL care symptom management and strategies to meet those goals Develop standardized assessment tools for symptoms and other care needs, evidence around frequency of assessments, and medication choices for different symptoms Define optimal processes for withdrawal or withholding of life-sustaining therapies (e.g., terminal weaning vs. direct extubation, location of withdrawal, patients with chronic ventilatory support, chronic circulatory support, and extracorporeal membrane oxygenation) Identify strategies for management of symptoms refractory to conventional treatments (e.g., palliative sedation) Expand studies of noninfant populations Identify best practices for managing symptoms such as dyspnea, agitation, and pain at EOL Develop symptom assessment tools tailored for nonverbal or neurologically impaired pediatric patients

(Continued)

TABLE 3. (Continued)
Research Priorities

Topic	Research Priorities
HCP palliative care education	Evaluate impact of HCP education on patient-and family-important outcomes (e.g., satisfaction with communication, satisfaction with symptom management, parental mental health and grief) Evaluate impact of education on outcomes for HCP (e.g., wellbeing, burnout, workforce retention) Conduct longitudinal follow-up of outcomes (e.g. sustained self-efficacy, longer term patient-and family-impacts) Examine cost-efficacy of various educational interventions Standardize educational interventions and assessments using standardized frameworks for reporting impact Explore the use of simulation and digital platforms to deliver scalable palliative care education
Bereavement support programs and interventions	Conduct more causal studies (whether using historical data/controls or RCTs) to assess impact of bereavement care on bereaved family outcomes Evaluate optimal processes, including timing of bereavement care, involvement of siblings, cultural tailoring Examine cost and cost-effectiveness considering impact on parent/sibling outcomes (mental health, social outcomes, employment/education, etc.) Evaluate how the timing and personalization of bereavement outreach impacts family outcomes Assess the impact of legacy-building and spiritual care practices on bereaved families
Addressing disparities in EOL care for PICU/ cardiac ICU/neonatal ICU patients and families	Conduct qualitative and mixed-methods research that highlights the experience of marginalized populations during pediatric and neonatal EOL care in the ICU Evaluate and describe the impact of systemic disadvantage and structural inequities on key outcomes in EOL care (e.g., urban vs. rural, high-income vs. low-income countries) Identify drivers of disparities in EOL ICU care (e.g., disparities in access to and delivery of services like ACP, child life, bereavement care) Test interventions to address disparities Address underrepresentation of historically marginalized populations in PPC intervention research Promote community-engaged research to co-develop culturally responsive EOL interventions Evaluate strategies to increase palliative care exposure and improve palliative care mentorship for underrepresented minority students Evaluate strategies to improve diversity among PPC scientists

ACP = advance care planning, EOL = end-of-life, HCP = healthcare provider, PPC = pediatric palliative care, RCT = randomized controlled trial.

of cultural humility; 2) identifying and addressing structural racism and institutionalized discrimination; and 3) engagement of patient, family, and community perspectives and experiences in the care process.

A summary of the indirect evidence supporting the good practice statement and the process for developing it are presented in the Supplementary Materials (Section 5, <https://links.lww.com/PCC/C707>).

Patients and families from disadvantaged, minoritized or marginalized populations may face multiple barriers to receiving high-quality EOL care, including under recognition and undertreatment of pain, language and communication barriers, cultural stereotypes, distrust and misunderstanding, and biased assumptions. The recommendations in these guidelines may have limited benefit for these populations if current disparities are not addressed. For example,

PPC could improve health equity by supporting ACP, improving goal-concordant care, empowering families to participate in shared decision-making, and providing an additional layer of psychosocial and spiritual support for marginalized patients and families. However, if these families are unable to access PPC, or if effective delivery of PPC is impaired by bias and distrust, then equity in EOL care is unlikely to increase (108–110). This best practice statement encourages ICU teams to intentionally assess for and address these barriers at individual, team, and organizational levels, emphasizing the importance of engaging patients, families, and communities in the process.

RESEARCH AGENDA

These 2026 SCCM guidelines underscore the critical need for continued research to strengthen the evidence base for EOL care in pediatric and neonatal intensive care settings. Key cross-cutting priorities include the development and validation of more robust tools to assess symptom burden and the experiences of patients and families. There is a particular need for studies that generate direct evidence of patient- and family-centered outcomes resulting from palliative and EOL care interventions. Advancing the field also requires research designs that can support causal inference, such as longitudinal studies, and RCTs. Designs that do not require randomization of interventions, such as interrupted time series analyses, historical control groups, or novel approaches like target trial emulation (111), may help mitigate concerns regarding equipoise in this sensitive population. Hybrid effectiveness-implementation trial designs are especially important for understanding not only whether interventions work but also how they can be successfully implemented in real-world settings. Notably, there is a significant gap in evidence related to the cost-effectiveness of interventions, their adaptation across different healthcare resource settings, and their impact on health equity. A detailed summary of research priorities for each topic area addressed in these guidelines is provided in **Table 3**.

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- 1 Department of Anesthesiology Critical Care Medicine and Center for Bioethics, Children's Hospital Los Angeles, Los Angeles, CA.
- 2 Department of Pediatrics, Keck School of Medicine of USC, Los Angeles, CA.
- 3 Boston College Connell School of Nursing, Chestnut Hill, MA.
- 4 NYU Grossman School of Medicine, New York, NY.
- 5 McMaster University, Hamilton, ON, Canada.
- 6 Division of Pediatric Critical Care, Department of Pediatrics, University of Miami Miller School of Medicine and Holtz Children's Hospital, Miami, FL.
- 7 University of Miami Institute for Bioethics and Health Policy, Miami, FL.
- 8 Division of Neonatology, Department of Pediatrics, Vanderbilt University Medical Center, Nashville, TN.
- 9 Department of Spiritual Care, Monroe Carell Jr. Children's Hospital, Vanderbilt University Medical Center, Nashville, TN.
- 10 Transforming Chaplaincy at Rush University, Chicago, IL.
- 11 OSF Healthcare Children's Hospital of Illinois, Peoria, IL.
- 12 University of Utah, Salt Lake City, UT.
- 13 Nemour's Children's Health, Wilmington, DE.
- 14 Society for Critical Care Medicine, Mount Prospect, IL.
- 15 Lurie Children's Hospital, Chicago, IL.
- 16 Ethics Consultants, Inc., San Diego, CA.
- 17 University of Washington School of Medicine, Seattle, WA.
- 18 Seattle Children's Hospital and University of Washington, Seattle, WA.
- 19 Courageous Parents Network, Boston, MA.
- 20 Presbyterian Campus Ministry of Raleigh, Raleigh, NC.
- 21 Boston Children's Hospital, Boston, MA.
- 22 Department of Pediatrics, Harvard Medical School, Boston, MA.
- 23 Johns Hopkins School of Medicine, Baltimore, MD.
- 24 Advocate Children's Hospital, Park Ridge, IL.
- 25 Nationwide Children's Hospital and The Ohio State University College of Medicine, Columbus, OH.
- 26 Child Life Consulting, LLC, Philadelphia, PA.
- 27 Northwell Health, New Hyde Park, NY.
- 28 Division of Pediatric Critical Care Medicine, Cohen Children's Medical Center, New Hyde Park, NY.

[†]Family representative with lived experience as a parent of a child who died from serious illness.

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For information regarding this article, E-mail: sderrington@chla.usc.edu

The Society of Critical Care Medicine (SCCM) guidelines are intended for general information only, are not medical advice, and do not replace medical professional advice, which should be sought for any medical condition. The full disclaimer for guidelines can be accessed at: <https://sccm.org/Clinical-Resources/Guidelines/Guidelines>. The American College of Critical Care Medicine (ACCM), which honors individuals for their achievements and contributions to multidisciplinary critical care medicine, is the consultative body of the SCCM, which possesses recognized expertise in the practice of critical care. The ACCM has developed administrative guidelines and clinical practice parameters for the critical care practitioner. New guidelines and practice parameters are continually developed, and current ones are systematically reviewed and revised. Librarian services, systematic review, and analysis for these guidelines were provided contractually through the Guidelines in Intensive Care Medicine, Development and Evaluation Group, McMaster University, Canada. Methodologists served as expert panel members specializing in this area. The guidelines have been sponsored by the following societies: 1) American Academy of Hospice and Palliative Medicine; 2) American Academy of Pediatrics; and 3) American Association of Critical-Care Nurses.

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