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Pediatric End-of-Life Guidelines & Insights

In this World Shared Practice Forum Podcast, Drs. Danielle DeCourcey and Sabrina Derrington provide their insight on the methodology and development of the 2026 Guidelines on the Care and Management of Pediatric and Neonatal Intensive Care Patients at the End-of-Life, sharing actionable guidance for clinicians at the bedside. The authors review GRADE methodology and provide context behind the conditional recommendations. The speakers reflect on next steps including implementation, research, and addressing disparities in end-of-life care.

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Initial publication:
August 25, 2026

Sarah Marcley *00:04*
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Jeff Burns *00:18*
Welcome to the OPENPediatrics podcast. I'm Jeff Burns at Boston Children's Hospital, and today we're going to have a special conversation about the recently published 2026 guidelines on the care and management of pediatric and neonatal intensive care patients at the end of life. These guidelines were published in the April issue of Pediatric Critical Care Medicine, and that citation accompanies this podcast. We're going to have a conversation today with the two co-chairs to get their insights on what is new or different, or in their view, significant about these guidelines. First, let me introduce Sabrina Derrington. Dr. Derrington is the director of the Center for Bioethics and a critical care attending physician at Children's Hospital of Los Angeles and associate professor of clinical pediatrics at the Keck School of Medicine at USC. Sabrina, welcome to OPENPediatrics Podcast.

Sabrina Derrington *01:14*
Thank you, Jeff. It's so great to be here with you today.

Jeff Burns *01:17*
And the other co-chair was Dr. Danielle DeCourcey. Dr. DeCourcey is associate chief division of medical critical care and department of pediatrics at Boston Children's Hospital and associate professor of pediatrics at Harvard Medical School. Danielle, welcome to the World Shared Practice Forum on OPENPediatrics.

Danielle DeCourcey *01:36*
Thank you, Jeff. I'm delighted to be here.

Jeff Burns *01:38*
Danielle, can I turn to you first. What prompted the SCCM [Society for Critical Care Medicine] to develop these guidelines, these end of life care guidelines for infants and children?

Danielle DeCourcey *01:49*
Yeah, I'd say the timing really came down to the convergence of a few things. There was a retreat that sparked kind of the right conversations, an SCCM revision process that created an opening and a gap in guidance that pediatric and neonatal ICU teams had been working around for a long time. Sabrina and I met at a retreat for pediatric intensivists and ethicists in 2023 and that group spent a lot of time talking about the hardest situations we face in our pediatric ICUs. And those conversations kept circling back to the same question, how do we provide the best possible care for pediatric patients and their families when the stakes are highest, and this is particularly around end of life care. Around that same time, we learned that SCCM had approved a revision of its 2008 consensus guidelines for end of life care in the ICU, and that that revision was going to be really adult focused. Although the original 2008 guidelines did include some pediatric content, the emphasis was not really on guiding clinicians that are caring for pediatric and neonatal ICU patients. So it really felt like the right moment for us to ask whether we needed dedicated pediatric guidance, especially given the evolving complexity of the children we care for in our ICUs, and whether or not SCCM would be interested in supporting that work. And I think the need was clear to them, because most children who die do so in the hospital, and most of these deaths happen in our ICUs. This is really some of the most complex and important care we provide in pediatric critical care, yet the teams in our PICUs and cardiac ICUs and NICUs have never had dedicated evidence-based guidance specific to their patients. So we really wanted to bring together the best available evidence and create practical guidance that actually felt relevant to the clinicians that do this work every day.

Jeff Burns *03:38*
Sabrina, anything to add to that?

Sabrina Derrington *03:41*
Yeah, I think Danielle really summed it up nicely. One of the things that we were most excited about in thinking of pulling this together was the opportunity to include our neonatology colleagues who historically haven't been as much a presence in some of the Society for Critical Care Medicine activities, but we felt it was really important to have neonatology presence and on the panel for these guidelines, because quite honestly, we are taking care of neonatal patients in ICUs, cardiac ICUs, and pediatric ICUs, and we wanted to have it be really a continuum from birth through the young adults that we also end up caring for, so just trying to be as inclusive as possible.

Jeff Burns *04:35*
Well, you know, as you both have just described, to dedicate this to the care of infants and children was needed. I'm thinking I've been around long enough to remember over 25 years ago, Bob Truog led the first two SCCM guidelines on end of life care, but Danielle, as you noted, it was a global look at end of life care, mostly centered though on the adult patient, and there was just, you know, there was reference to children, but, but just reference, not exclusively devoted to this. So this justification and this need certainly rings true to me. Sabrina, could I turn to you now? What would you say are the salient findings of the 2026 guidelines on end of life care for infants and children, and in particular, in your view, which recommendations are most actionable at the bedside today?

Sabrina Derrington *05:28*
Yeah, thanks. So it was actually quite challenging for Danielle and I to narrow our focus to just five PICO questions, but in that process we focused on advanced care planning, initiating goals of care discussions with families, which we felt was something that really should be a core skill for all critical care providers in any setting in pediatrics. We had some discussions early on about the fact that ideally those discussions are occurring with patients who have life-limiting or or serious illness diagnoses, even before they come to an ICU setting, but that, that doesn't always happen, and so, as critical care professionals, we wanted that to be a real focus, and it's easily implementable too, right, these are kind of core skills in communication and in listening, and that can be incorporated throughout the trajectory of a child's serious illness. So just wanted to highlight that one, and then another really key focus for us was recognizing the importance of understanding how to balance consultation of palliative care specialists with developing primary palliative care skills. And one of the challenges that we had in putting these guidelines together was recognizing that there are many different levels of resource settings, right. So many of us who were a part of developing the guidelines are working in academic centers where perhaps we're better resourced in terms of access to subspecialty palliative care providers and teams. But that's not the case everywhere, and so we really wanted these guidelines to be things that could be implemented in many different levels of resource settings, both here in the US and abroad, and so the recommendation specifically around pediatric palliative care consultation was probably the one that we worked on the most in terms of looking at timing, and how to implement that, and when to implement it in these different resource settings.

Jeff Burns *08:13*
Well, as the current president of the World Federation of Pediatric Intensive and Critical Care Societies, I'm awfully glad to hear that. You know, as I think we all know. Most of the world resides in low and middle income countries; that's where children are, that's where children are who are facing the greatest burden of disease. So I'm awfully glad to hear that you're making an attempt to make these practical across many resource environments. Danielle, same question to you. In your view, what are the which of these recommendations are most actionable at the bedside today?

Danielle DeCourcey *08:46*
Yeah, I mean, I would say a couple of things. One, you know, I think the most important finding from the guidelines is really simple. And it's that end of life care in pediatric and neonatal ICUs needs to be approached as a core part of high quality care for critical care clinicians. And we know that, based upon the best available evidence, the guidelines support five practices, as Sabrina alluded to: advanced care planning, pediatric palliative care consultation, systematic symptom assessment and management, primary palliative care education for clinicians, and bereavement care. And the guidelines also included a good practice statement that focused on addressing disparities and end of life care. And I guess what I'd emphasize is none of this should feel exotic. The leadership group and our panel chose clinical questions that really reflect the things that families remember. Did we listen? Did we understand what mattered to them? Did we communicate clearly? Did we manage their child's suffering? Did we help them to make decisions they could live with after their child died? And did we provide support before, during, and after their child's death? I would agree with Sabrina in that the most immediately actionable recommendation is really around advanced care planning. We are already having these conversations every day in our ICUs. And the question is not really whether we're having them early enough or skillfully enough or consistently, and the question really is, are we are we doing those things. And again, advanced care planning is not about getting families to make a particular decision. It's really

about understanding what matters most to them before crisis ensues, and everybody is in reaction mode. And what I like about that recommendation is it doesn't require every ICU to build a new system or program before getting started. At its core, it's just about creating a structured way to ask families about their hopes and fears and goals and preferences, and then making sure we use that information to inform their child's care plan. I think that recommendation gives us both permission and an obligation to make the conversations we're already having more intentional. And then lastly, I would just say that a big takeaway is that not every ICU needs to do the same thing the same way, that's not what the guidelines are saying. They're saying that every ICU really needs a reliable way to bring palliative care principles into the critical care practice. Whether that's asking what matters, communicating clearly, treating suffering, or supporting families, and we have to do that work consistently and equitably.

Jeff Burns *11:21*
You're both being so articulate, and of course, what you say is ringing true to me as an intensivist, and I especially like kind of the pillars that you're describing, which are, you know, not rigid and needs to be implemented the same way in every environment. It's a very compelling approach. Danielle, can I stay with you? You know, I'm always a little reluctant to ask the limitations question. You know, what limitations do you see here in the development of these guidelines? Because it seems to be critical, but of course it's just necessary part of an academic discussion, you know. What do you see as the limitations, and in particular, how should we interpret the fact that all the recommendations are quote unquote conditional recommendations?

Danielle DeCourcey *12:14*
Yeah, I'd say the biggest limitation is the evidence base. And all five recommendations are conditional, because the certainty of evidence was very low, and a big part of that is the lack of randomized clinical trial data in this area. Most of the evidence comes from observational studies, cross-sectional work, and qualitative research, and those studies are incredibly important, especially in our field, where RCTs are really hard to do. But they make it harder to say with confidence that a specific intervention caused a specific outcome. But I'd be really careful not to let low, very low certainty evidence get translated into these things don't matter. That's not what the guidelines are saying. And I think to understand what the conditional recommendations actually mean it helps to understand how they were developed. Like all SCCM guidelines, we use the GRADE methodology, which is a structured approach to evaluating evidence that relies on systematic reviews and evidence to decision frameworks. And then the panel, our wonderful multidisciplinary panel, used that information to weigh the evidence and reach each recommendation. And in GRADE, a conditional recommendation reflects uncertainty, but that uncertainty can come from the evidence itself, it can come from differences in feasibility and resources, or from variability in how patients and families weigh the benefits and burdens of an intervention. The GRADE process is appropriately strict, so that expert judgment can simply turn low certainty evidence into high certainty evidence. But conditional doesn't mean optional or weak or unimportant. It means the recommendation is built on the best available evidence that is interpreted through a rigorous process that also weighed feasibility, acceptability, equity, and outcomes that that really matter to patients and families. So clinicians should apply these recommendations thoughtfully with the specific child, family, and clinical situation and local resources in mind.

Jeff Burns *14:17*
And Sabrina, anything to add to that, limitations of the guidelines and conditional recommendations.

Sabrina Derrington *14:26*
I really appreciate how Danielle explained what that means when we have a conditional recommendation, and I completely agree. One of, I mean, I'll just say honestly that it was frustrating for us to have these questions that we were hoping to answer that we really felt were so important to our work in critical care and for our patients and families, and yet the quality of the evidence just wasn't there to be able to offer a stronger recommendation. And yet one of the most important things that came out of that really extensive review of the literature and all of our discussions on the panel was to identify these priorities for research, right. And we're, we're really hoping that people will read these guidelines, that they will incorporate these core practices of primary palliative care into their intensive care practice, but then that they'll go further, right. And we're hoping that collaborative efforts to address some of these research priorities will really take the field to the next level and where it needs to be to be able to have more certainty around not so much the question of whether we should be providing palliative care in the ICU, but how best to do it, and especially under different circumstances.

Jeff Burns *15:55*
Well, you know, in listening to you both describe this, and Danielle, you said it so well, you know, I'm thinking of the famous quote: not everything that can be counted counts, and not everything that counts can be counted. The RCT is appropriate in many environments, but not every environment.

Danielle DeCourcey *16:12*
That's right.

Jeff Burns *16:13*
And I just can't imagine how we would do an RCT on this, and so I think the approach that you've taken is appropriate and the absence of RCTs, I think you, you both well describe, is not in any way a criticism or a fault. There's still plenty of plenty of reasons to go forward with the work that you've produced here. Sabrina, you were touching on this at the end of your last answer, but I'm going to turn to you first again. You know what lessons can the pediatric, well pediatric and neonatal critical care community take from your findings.

Sabrina Derrington *16:52*
Thank you, Jeff. So you know we kind of touched on this question of implementation in different resource settings and feasibility of implementing some of this work. And you know, I think I would worry that someone in a, in a setting where perhaps they don't have access to a palliative care consultant might say, well, this isn't really something that that I can do. I'm not going to be able to consult palliative care. But what I would say is that palliative care and focusing on guiding families in making difficult decisions, thinking about their goals and values for their child, addressing uncomfortable symptoms, and really supporting that whole process is a continuum. And so what I would hope that people would take away from this is there's something here that can be implemented for every child and family at every stage of the process. And the resources that we have put together that are available on the SCCM website should help to do that. The implementation toolkit has a really fantastic assessment tool for sort of looking at what are the biggest needs at my institution, what are the resources that I have available. And then from that, how are we going to balance training our ICU staff to be able to do a lot of this work, perhaps advocating for more subspecialty palliative care resources, and kind of looking even outside of the hospital setting in the community for creative ways to bring in that specialty

expertise. There's a lot of different ways that this could look, but the focus is on providing high quality end of life care for all infants and children.

Jeff Burns *18:52*
And Danielle, anything to add to that?

Danielle DeCourcey *18:54*
Yeah, I mean, I totally agree, Sabrina, and I would say another lesson I think that people should take away is that structure matters, right. Compassion is really important, but compassion alone doesn't make care reliable. If we want our families to receive consistent care, we need systems that support communication and symptom management, and clinician education, and bereavement care. I think symptom management is actually a really good example, because the guidelines support a systematic approach rather than an ad hoc one. And this doesn't mean that every child or family gets the same care. It means we have reliable ways to assess and treat pain, dyspnea, distress, and within that we can still tailor care to what matters most to the child and family. The goal is really to make care less dependent on who happens to be on service or who feels comfortable providing end of life care. And then I guess I would say the last lesson, and it's something we've already touched on, but it's definitely one that's surprised me and humbled me. It's that you know our science hasn't caught up to our expertise at the bedside, and we really need to get much better at measuring the things that we value. As Jeff mentioned, you know, not everything that counts can be counted, and this is especially true in end of life care. Many of our families describe things that are most important to them, and these things are really hard to measure. But the guidelines also made it clear to me that if we don't get better at measuring these outcomes, they will remain really hard to study, it'll remain really hard to improve them, or to build them into care in a reliable way.

Jeff Burns *20:38*
Well, Sabrina, you referred to resources available on the SCCM site, and I will make sure that those resources are also published on the WFPICCS.org website. So that it's really open and available to colleagues around the world, since, of course, many of our colleagues in low and middle income countries don't - they're not members of SCCM, obviously, but we will make sure that they are on WFPICCS.org, W-F-P-I-C-C-S.org. Danielle, coming back to you, I distinctly recall a couple of months ago you were and I were talking and you said, you know, this this took several years of work, and this is often not appreciated by people like me, who simply read it when it comes out. But you both put in literally years of effort on this, so I can't help but wonder, how you both of you, who are co-chairs of this publication, again in the April issue of Pediatric Critical Care Medicine, the April 2026 issue of Pediatric Critical Care Medicine, what are the next steps for these guidelines? And I can imagine that you might have one of two responses. One might be, listen, we just finished several years of work, don't ask me what's next. On the other hand, who better than you both to know, you know what, it was a lot of work, but we also know what's missing, or what needs to be the next step. So, Danielle, you first, and then Sabrina. Danielle, how do you answer that question? What are the next steps for the guidelines?

Danielle DeCourcey *22:18*
Yeah, I mean, I think there's two parallel next steps, and we've touched on both of them. The first step really is around implementation. And again, having that toolkit available, I think, will be very helpful to help local ICU leaders be able to assess needs and identify barriers and adapt the recommendations to their settings. You know, this matters, obviously, because not every unit has the same staffing or

palliative care access or child life support that that many of the institutions that that we worked with or that are in SCCM have. And I think this is one area where our the expertise of our multidisciplinary panel was really important, right. And thinking through feasibility and acceptability and implementation barriers, and how these recommendations may actually work in diverse clinical environments. And then I think the second step is really research, for me, this is probably the most important message of the guideline. We need a much stronger research agenda in pediatric and neonatal end of life care. And this means developing, validating, and standardizing meaningful outcome measures, especially around goal-concordant care. It means testing different models of palliative care integration, or advanced care planning, or symptom management. And we need more studies that help us understand cause and effect, right? In some cases, that may be an RCT, but in other cases, it may be an interrupted time series, or a hybrid effectiveness implementation design, or a longitudinal study. This is a really hard area to study, but there's rigorous ways to do it, and we should take kind of best practices from other fields in trying to figure out how to move this work forward. I think right now many of us believe these practices matter because we see their impact at the bedside, but the next step is really trying to build the evidence to show what works best for which patients and families, and in which ICU settings.

Jeff Burns *24:24*
And Sabrina, your thoughts on next steps for the guidelines.

Sabrina Derrington *24:28*
Yeah, so for me, really, the most important next step relates to our good practice statement. And we didn't talk as much about that. We were only allowed five PICO questions, and yet I feel like the good practice statement is really one that all of our panelists felt very strongly about the importance of actively addressing disparities in pediatric end of life care and eliminating barriers to high quality palliative care for all patients and families, particularly marginalized communities and populations. We see a breakdown in trust occur when there are language barriers that aren't adequately addressed, or when there are cultural differences that aren't appreciated, or when people come into the ICU with a critically ill, perhaps dying child, and they've already experienced discrimination in healthcare settings. And without addressing that, without getting at that core need to build trust and to connect on a human level, we really can't do all the rest of the stuff that's in these guidelines. So that's what I want to keep working on, and I know many of our co-panelists felt the same.

Jeff Burns *25:51*
You're both very articulate and moving and empowering, I guess is the word. It's motivating me, even at the end of my career, to work harder at this. Last question for you both. What book have you read that really moved you, and you want to share with the audience? Danielle, can I go to you first?

Danielle DeCourcey *26:16*
Sure, I'm sort of way on the most recent book I read, which was The Correspondent. It's really a beautiful book that's told through letters, and it's about relationships and the way people keep learning and changing across a lifetime. And I would say, what stayed with me was the sense that it's never too late to become more open, or to repair something that feels irreparably broken, or to let yourself be changed by a connection with another person. And I'd say this feels very connected to end of life care, right? At the bedside, we meet families at a moment when so much can feel broken or uncertain, and these families bring with them different histories and cultures and values, and our job is really to meet them where we are, right, without assuming we know what matters most to them. It's to stay open and

to listen carefully, and to try to understand what they're carrying, and to use our expertise to support decisions that feel right for their child. I will say, I've been thinking a lot about the idea of connection lately with the World Cup, which has been so inspiring. There's something so powerful about people coming together across nationality and race and politics to care about the same thing. I guess what strikes me is that, like, at its best, the World Cup is reminding us that showing up for each other across differences is possible. It's still possible, and honestly, that feels like something worth holding on to right now, both at the bedside and beyond it.

Jeff Burns *27:46*
Danielle, that's just a wonderful description of this book. One more time, the title and author of this book.

Danielle DeCourcey *27:54*
The Correspondent by Virginia Evans.

Jeff Burns *27:56*
Sabrina, a book that really moved you, and you want to share with the audience.

Sabrina Derrington *28:01*
Sure, so this is actually a book that I've read again and again from the time that I was a fellow in critical care and through my whole career, and I keep coming back to it because it's so meaningful to my life and to my work, but it's Annie Dillard's Pilgrim at Tinker Creek. And Annie Dillard loves the natural world, and in that book, a lot of the of what she's writing about is recognizing that there is darkness coexisting with light. It's the beauty and horror of nature and of being human, and what has always meant so much to me in that is that, yeah, we walk through these really awful moments, these incredible losses, these tragedies, and yet there is so much beauty and so much meaning that carries us through that, so highly recommend, and I, it will continue to be an inspiration to me.

Jeff Burns *29:09*
Oh boy, I always love hearing these recommendations rush out to the library. Well, listen, thank you so much to you both. We've been speaking with the co-chairs of the 2026 guidelines on the care and management of pediatric and neonatal intensive care patients at the end of life, as published in the 2026 April edition of Pediatric Critical Care Medicine. Doctors Sabrina Derrington and Danielle DeCourcey, you're both, you're both very passionate about your work. It comes through, you're very articulate, and you're empowering as I said earlier, and on behalf of colleagues around the world, we thank you for your years of effort in producing these guidelines and providing materials and resources for us to improve our care in this absolutely fundamental area of care. Thank you both.

Danielle DeCourcey *30:07*
Thank you.

Sarah Marcley *30:09*
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Articles Referenced:

Derrington S, Broden Arciprete EG, Lin MC, et al. Executive Summary of Society of Critical Care Medicine 2026 Guidelines on the Care and Management of Pediatric and Neonatal Intensive Care Patients at the End of Life. Pediatr Crit Care Med. 2026;27(4):487-493.

The Correspondent by Virginia Evans

Pilgrim at Tinker Creek by Annie Dillard