

Original Publication

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# Newborn Care Curriculum: Palliative Care for the Newborn

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## Abstract

**Introduction:** Because pediatric hospitalists have increasing responsibilities in newborn hospitalization, training in perinatal palliative care is beneficial. A 2015 needs assessment revealed 68% of surveyed pediatric hospitalists were interested in more education on this topic. Thus, this learning module was designed to provide a concise, easy-to-use introduction to palliative care for the newborn. **Methods:** This module was developed as part of the computer-based Newborn Care Curriculum to fill a gap in educational resources on perinatal palliative care. The primary tool in this learning module is a PowerPoint slide show with a script in the notes section. Using the presenter mode to view the PowerPoint slide show allows the learner to simultaneously view the slides and read the script for instruction. This module was tested by members of the pediatric hospitalist division at Children’s National Health System in Washington, DC. Participants completed a pretest, posttest, and module evaluation. While tested as a self-study tool, the module may also be used in a small-group teaching setting. **Results:** The module was well received during the trial. The average posttest score was 96%, compared to pretest scores of 90%. Learners’ comments were overwhelmingly positive, and constructive feedback has been addressed. **Discussion:** This module provides pediatric hospitalists and others who care for newborns with a well-received introduction to perinatal palliative care. The computer-based format of the module adds to its uniqueness and utility.

## Keywords

Palliative Care, Hospice, Newborn, Hospitalist, Perinatal

## Educational Objectives

By the end of this session, learners will be able to:

1. Define basic principles of pediatric palliative care and how they apply to caring for a newborn with a life-limiting illness.
2. Recognize diagnoses and medical conditions of the newborn amenable to palliative care.
3. Identify perinatal palliative care and services provided from pregnancy through bereavement.
4. Describe strategies to communicate with families regarding birth planning and goals of care.
5. Describe approaches to providing palliative care to a newborn at delivery and in the immediate newborn period.
6. Identify when and how to refer to subspecialty palliative care or hospice services.

## Introduction

The role of pediatric hospitalists in community hospitals, including in newborn care, is expanding.<sup>1</sup> Pediatric hospitalists, particularly those working in a community hospital setting and attending deliveries, are likely to encounter situations where training in perinatal palliative care is beneficial. They may have less access to subspecialty palliative care teams or providers and less access to educational opportunities. In addition, the Society of Hospital Medicine’s Pediatric Hospital Medicine Core Competencies include management of the newborn in the delivery room, well-baby nursery, and level II nursery.<sup>2</sup> A needs assessment completed in 2015 surveying the American Academy of Pediatrics’ Section

## Appendices

- A. Palliative Care for the Newborn Module.pptx
- B. Presenter View Instructions.docx
- C. NCC PC Pretest.docx
- D. NCC PC Pretest With Answers.docx
- E. NCC PC Posttest.docx
- F. NCC PC Posttest With Answers.docx
- G. Palliative Care for the Newborn Module Evaluation.doc
- H. Sample Birth Plan.docx
- I. Sample Birth Plan.pdf
- J. NCC PC Module Image Citations.docx

*All appendices are peer reviewed as integral parts of the Original Publication.*

on Hospital Medicine LISTSERV on topics in newborn care found that 68% of the participants desired more information on palliative care of the newborn, while most expressed interest in computer-based learning activities.<sup>3,4</sup>

Perinatal palliative care includes palliative care services starting in pregnancy and continuing through birth, the newborn period, and the death of the infant, as well as perinatal hospice care. Like the broader field of pediatric palliative care, perinatal palliative care has gained more attention over the last 2 decades and is now a well-described discipline.<sup>5</sup> Indications for considering a neonate for palliative care and standards of practice, based on broader principles of pediatric palliative care, have been well defined.<sup>6,7</sup> Perinatal palliative care is included as an important component in the national standards for pediatric palliative care,<sup>8</sup> and national, as well as international, guidelines for perinatal palliative care have been developed.<sup>9-12</sup> These guidelines advocate for the importance of offering palliative care for families whose newborns are diagnosed, either pre- or postnatally, with a life-limiting illness. They describe eligibility criteria, prenatal counseling, birth planning, communication, decision-making around life-sustaining interventions or technology, pain/symptom management postnatally, end-of-life planning, and bereavement support.

Resources are available for training in perinatal palliative care and palliative care of the newborn. However, many are only available through palliative care organizations, which are likely targeted more toward palliative care providers who seek continuing education on those sites. Training courses, such as the End-of-Life Nursing Education Consortium, are in-person multiday trainings. Few peer-reviewed educational modules that are available for self-study exist on newborn or perinatal palliative care. Existing peer-reviewed educational resources include a case on newborn end-of-life care,<sup>13</sup> as well as a series of standardized patient neonatal ethics cases featuring a case on unexpected birth malformation.<sup>14</sup> In addition, simulation modules on delivering bad news targeted to neonatal-perinatal providers have been published.<sup>15</sup> To our knowledge, there are no peer-reviewed publications of educational resources addressing the specific topic of perinatal palliative care along the entire spectrum from pregnancy to after birth. In addition, there are no resources available in a self-study mode that provide training in newborn or perinatal palliative care specifically to the audience of non-neonatologist, non-palliative-care-trained pediatricians who staff hospital nurseries. This is an important gap we hope to fill with this resource.

No prerequisite training is needed for this module. It was developed by pediatric hospitalists as part of the larger Newborn Care Curriculum (NCC) at Children's National Health System in Washington, DC; however, the content of the module is independent of the others in the NCC.

## Methods

This palliative care learning module was developed in response to a 2015 needs assessment revealing interest in further education in palliative care for the newborn and in computer-based learning formats. The module was initially developed for pediatric hospitalists, but other newborn care providers including nurses, medical students, residents, and physician assistants may find it beneficial. It could also be used by learners or providers in the field of palliative care interested in learning more about perinatal palliative care. The module has features that allow for use as a self-study tool or for small-group settings.

The PowerPoint slide show (Appendix A) is the primary learning tool in the module. Included with the slide show is a script in the notes section. When applicable, the click button indicates that an animation feature in the slide is activated by clicking the arrow or mouse to advance. Using the presenter view of the PowerPoint application, learners can read the script as they advance slides and study at their own pace. Instructions for the presenter view feature of PowerPoint are included in Appendix B. Appendices C and D are the pretest without and with pretest answers and explanations, respectively. Appendices E and F are the posttest without and with answers and explanations, respectively. Appendix G is a postmodule evaluation. Learners are provided with a sample birth plan in Appendices H and I. Appendix J provides image citations for the slide show.

When using the module as a self-study tool, learners are encouraged to assess their baseline knowledge by completing the pretest prior to viewing the PowerPoint slide show in the presenter view format. Upon completion of the module, learners' knowledge can be reassessed with the posttest. The sample birth plan is a tool that facilitates advancing the gained perinatal palliative care knowledge into clinical practice.

When using the module in a small-group teaching setting, the instructor can assess baseline knowledge of learners by administering the pretest prior to giving the talk. The instructor can project the PowerPoint slide show and read the script in the notes section to present the topic. The posttest can reassess learners' progress, and the module evaluation can provide the presenter with feedback.

This perinatal palliative care module was distributed to interested members of the Children's National Health System pediatric hospitalist division in 2016 and further evaluated as a self-study tool. Assessment of the module's utility was based on participants' pretest scores, posttest scores, and postmodule evaluation.

## Results

This module was completed by 12 members of the pediatric hospitalist division at Children's National Health System in Washington, DC, in the spring of 2016. Seventy-five percent of these learners reported newborn care as part of their current clinical responsibilities. The results of the postmodule evaluation are presented in the Table. A 5-point Likert scale was used to rate the module, with 1 = *strongly disagree* and 5 = *strongly agree*.

**Table.** Postmodule Evaluation Results

Evaluation Question	Average Score <sup>a</sup>	Agree or Strongly Agree
This learning activity met the stated learning objectives.	4.50	91.6%
Material presented in this learning activity was relevant to my clinical practice.	4.17	83.3%
Material presented in this learning activity will change my clinical practice.	3.42	41.7%
Material presented in this learning activity increased my comfort with teaching about this topic.	4.08	83.3%
This learning activity would be useful for small-group teaching.	4.50	91.6%
Format of this learning activity was appropriate for my learning needs.	4.58	100.0%
The format of this learning activity would be more effective with an audio narration.	3.83	58.3%

<sup>a</sup>On a 5-point Likert scale (1 = *strongly disagree*, 5 = *strongly agree*).

The module was highly rated (4.5 or higher) for meeting the learning objectives, usefulness for teaching small groups, and appropriateness of the format of the activity. Learners also rated the module highly in clinical relevance and their perception that it would improve comfort in teaching this topic. The lowest rating was for change in clinical practice.

Comments from participants were also solicited. Learners described the module as "excellent," "thorough," "complete," "informative," "relevant," and "well written." Learners commented that palliative care for the newborn was rarely discussed but very important. Several learners indicated that they most appreciated specific content, including reviewing a birth plan, steps/language in communicating with families, use of medications to relieve distressing symptoms, and enrollment in hospice. Constructive feedback included suggestions to feature a sample case, so an illustrative teaching case was subsequently added prior to publication.

The average pretest score was 90%, which increased only slightly to an average posttest value of 96% (unpaired *t*-test *p* = .058), not a significant change. Learners commented that some of the questions were too easy. The questions used in the study were thus revised to be more challenging and increase the opportunity for learning. The revised pre- and posttest questions are included in this publication.

## Discussion

This module covers the broad topic of perinatal palliative care in a short period of time appropriate for an independent learner. The topics of prenatal counseling in perinatal palliative care, communicating with families, developing a birth plan, hospice care, and end-of-life care for newborns could all be covered in

more detail in individual modules; thus, the level of detail achieved is limited. However, the goal is to offer general pediatricians an introductory exposure to palliative care with enough background and resources to allow them to provide a standard of care without being experts.

While this introductory perinatal palliative care learning module was well received in the self-study format, postmodule evaluations revealed that 92% of participants strongly agreed it would be beneficial in a small-group setting, while 83% agreed or strongly agreed that their comfort level in teaching this topic increased after completing this module. Future studies of the module as a small-group tool would be useful.

In addition, 42% reported that the material presented in the module would change their clinical practice. This demonstrates an important impact on a subset of learners. It is possible that some learners did not anticipate they would need to apply these skills based on their clinical responsibilities, since 25% of respondents did not provide newborn care and others might work in facilities where palliative care consultation services were available.

While 100% of participants agreed the format of this learning activity was appropriate for their learning needs, 58% felt the format would be more effective with an audio narration. This provides an opportunity for future enhancement of the module.

#### Limitations

This study was limited by its small number of respondents. In addition, the study group was limited to a single pediatric hospitalist division whose members may have had shared previous educational or clinical experiences and thus might not represent all pediatricians providing newborn care. Evaluation of the module was limited by the pre- and posttest questions being assessed as overly simple, which limited the ability to measure educational gains after completing the module. More challenging questions or a larger number of questions or cases could improve the assessment of educational outcomes. Finally, this module was assessed only via self-study and not for use in a small-group setting.

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Reported as not applicable.

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