Special Article

Development of a Pediatric Palliative Care Curriculum and Dissemination Model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics

Stefan J. Friedrichsdorf, MD, FAAP, Stacy Remke, MSW, LiCSW, Joshua Hauser, MD, Laurie Foster, MEd, Andrea Postier, PhD, MPH, Alison Kolste, and Joanne Wolfe, MD, MPH

Department of Pain Medicine (S.J.F., S.R., A.P., A.K.), Palliative Care and Integrative Medicine, Children's Hospitals and Clinics of Minnesota, Minneapolis, Minnesota; Department of Pediatrics (S.J.F.), University of Minnesota, Minneapolis, Minnesota; Dana-Farber Cancer Institute (J.W.), Boston, Massachusetts; Boston Children's Hospital (J.W.), Boston, Massachusetts; University of Minnesota School of Social Work (S.R.), St. Paul, Minnesota; Department of Medicine (Palliative Medicine) (J.H.), Northwestern Feinberg School of Medicine, Chicago, Illinois; Jesse Brown VA Medical Center (J.H.), Chicago, Illinois; and University of Minnesota School of Public Health (L.F.), Minneapolis, Minnesota, USA

Abstract

Context. Most children living and dying with serious illnesses experience high burden of distressing symptoms. Many seriously ill children and their families do not have access to subspecialist pediatric palliative care (PPC) services nor to clinicians trained in primary PPC. Lack of PPC education appears to be a significant barrier to PPC implementation.

Objectives. Description of the development and dissemination of Education in Palliative and End-of-Life Care (EPEC)-Pediatrics.

Methods. Funded through a U.S. $1.6 million National Institutes of Health/National Cancer Institute grant 2010–2017, this 24-module curriculum was designed to teach primary palliative care. The target audience included interprofessional pediatric hematology/oncology providers and all other clinicians caring for seriously ill children.

Results. The curriculum is delivered in a combination of online learning and in-person, face-to-face sessions. In addition, a one-day Professional Development Workshop was developed to teach EPEC-Pediatrics graduates, future "Trainers," thus becoming "Master Facilitators." Between 2012–May 2019, a total of 867 EPEC-Pediatric Trainers and 75 Master Facilitators from 58 countries participated in 17 *Become an EPEC-Pediatrics-Trainer* conferences and three Professional Development Workshops. The curriculum has also been adapted for large-scale dissemination across Canada and Latin-America, with translation to French and Spanish. Participants overwhelmingly report improvements in their PPC knowledge, attitudes, and skills, including teaching. Trainers subsequently anticipated improvements in patient care for children with serious illness at their home institutions.

Conclusion. EPEC-Pediatrics has developed into the most comprehensive PPC curriculum worldwide. It is highly adaptable for local settings, became self-sustaining and six conferences are offered around the world in 2019. J Pain Symptom Manage 2019;■:■–■. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Pediatric palliative care, education, curriculum, Train-the-Trainer, dissemination, post-graduate teaching

Address correspondence to: Stefan J. Friedrichsdorf, MD, FAAP, Department of Pain Medicine, Palliative Care and Integrative Medicine, Children's Hospitals and Clinics of Minnesota, 2525 Chicago Avenue South, Minneapolis, MN 55404, USA. E-mail: Stefan.Friedrichsdorf@childrensMN.org

Accepted for publication: June 10, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.06.008

Background

More than 21 million children worldwide would benefit from pediatric palliative care (PPC). Of those, over eight million children need specialized PPC services.[1] In the U.S. alone, a total of 41,881 children aged zero to 19 years died in 2014, more than 55% (23,215) of them were infants younger than one year.[2] Leading causes of deaths because of serious illnesses in children include congenital malformations and chromosomal abnormalities (5672), premature birth (4173), followed by malignancies (1838) and cardiac disease/diseases of the circulatory system (1083). Notably, although the prognosis for children with cancer has improved considerably over the past four decades,[3] malignancies remain the leading cause of non-accidental death in children older than one year in the U.S.[2,4]

Studies, especially among children with cancer, suggest that children with serious illness experience high symptom distress and poor quality of life.[5–11] Unfortunately, most distressing symptoms in children with advanced cancer (such as pain, dyspnea, and nausea/vomiting) are not treated, and when treated, therapy is commonly ineffective.[5–7,9,12,13] The only prospective study using self-assessment of pediatric patients with advanced cancer revealed many highly distressing symptoms including pain (58%), fatigue (41%), drowsiness (40%), anorexia (36%), nausea (34%), dyspnea (9%), and other symptoms.[13] Advances in the control of symptoms in children living with serious illness, such as cancer, have unfortunately not kept pace with treatment directed at the underlying disease.

In contrast, emerging research suggests that integration of PPC into the care of children with serious illness improves outcomes. For example, reports from bereaved parents showed that children with cancer who received PPC experienced less distress from pain, dyspnea, and anxiety during the end-of-life period,[7] and children who received pediatric palliative home care were more likely to have fun and to experience events that added meaning to life.[9] In addition, families who received PPC services report improved communication[14] and children receiving PPC experience shorter hospitalizations and fewer emergency department visits.[15,16]

Although high-quality PPC for children with serious illnesses is now an expected standard of medicine,[17] significant barriers remain to meet this standard. These include care related to reimbursement issues, the emotional impact of caring for seriously ill children, the lack of interdisciplinary PPC teams with sufficient staffing, and importantly, lack of formal education to meet the need.[18,19]

Education in PPC is in high demand worldwide.[20] Lack of clinician training, as well as education of families with children living with serious illness, has been cited as a major barrier to children and families accessing skilled palliative care.[21] In fact, professional education and development in palliative care is now encouraged in the recent Institute of Medicine report *Dying in America: Improving quality and honoring individual preferences near the end of life.*[17]

Although there are an increasing number of PPC programs in children's hospitals across the U.S., many are vastly understaffed.[22] Furthermore, the number of physician training slots for pediatric hospice and palliative medicine (HPM) specialists are not high enough to meet this need. In 2018, of more than 220 children's hospitals, only 38 U.S. institutions offered a total of 47 pediatric fellowships (or adult fellowships with a pediatric track) in HPM.[23] This is more than all other remaining PPC/HPM training programs worldwide combined. The number of pediatric patients needing palliative care will continue to exceed the number of palliative care specialists that programs can train.[24] Indeed, most seriously ill children will be cared for by their primary subspecialists and pediatric clinicians. Therefore, increasing PPC competencies in these clinicians is a critical need, and as a result we created the Education in Palliative and End-of-Life Care (EPEC)-Pediatrics program, a primary PPC curriculum. The purpose of this report is to:

1. Report on the development of the current most comprehensive PPC curriculum world-wide
2. Describe the curriculum's dissemination strategies
3. Present efforts and impact in training "Master Facilitators (MFs)," "Trainers," and "End-Users" worldwide

Part 1: EPEC-Pediatrics Curriculum Development

In response to the need for more widespread professional training in primary PPC and the gap between basic and advanced training in the prevention and treatment of pain and other distressing symptoms, EPEC-Pediatrics was conceptualized by a core investigator team (Appendix Table 1) and then funded through a $1.6 million NIH/NCI R25 grant. This program was adapted from the adult EPEC program with the pediatric content newly created after an extensive review of existing PPC curricula.[25–31] The adult EPEC program is a leading model for training clinicians in primary palliative care skills,[28] and is currently composed of 17

Table 1
EPEC-Pediatrics Modules and Objectives

Module Title	Objectives
M1. What is Pediatric Palliative Care (PPC) and Why Does it Matter: Palliative Care Overview	• Define PPC as a set of tasks • Identify predictable opportunities for palliative care intervention at different stages of disease • Describe when and how to use a subspecialty palliative care team • Evaluate myths and assumptions about PPC
M2: Child Development	• Learn typical phases of cognitive, psychosocial, and spiritual growth • Learn how children of different developmental capacity understand concepts of illness and death and how this can impact care planning • Learn interventions that can be used when working with children of diverse ages along the illness continuum and at end of life
M3: Family Centered Care	• Define FCC • Learn the four key principles in FCC • Describe strategies for delivering effective FCC in pediatric palliative care • Understand and reduce barriers to the delivery of FCC
M4: Grief and Bereavement	• Review theories of grief • Assess grief in children • Use developmentally based strategies to address grief • Discuss grief related to the loss of a child and strategies to address family grief
M5: Self Care for Professionals	• Understand how self-care is a core competency in palliative and end-of-life care • Recognize what triggers stress and burnout • Develop a self-care plan that reduces stress and fosters personal growth and well-being
M6: Team Collaboration and Effectiveness	• Identify the conceptual basis for teamwork in palliative care • Describe different types of teams in palliative care • Name specific advantages and challenges of teamwork
M7: Communication & Planning	• Describe the six steps of the SPIKES model for giving bad news • Detail reasons for communicating prognosis • Learn methods for communicating prognosis • Understand ways to elicit goals of care and to discuss advanced care planning
M8: Ethical & Legal Issues	• Place ethics in pediatric palliative care • Clarify role of parents as surrogate decision makers • Describe basic tenets of pediatric end-of-life care
M9: Teaching with EPEC-Pediatrics in the Face-to-Face Setting	• Describe how education can promote practice and systems change • Describe why it is important to identify the tension point for learners • Name three principles of adult learning • Design a training session using EPEC-pediatrics curriculum materials
M10: Multi-Modal Analgesia	• Review assumptions about opioid use in children • Evaluate the four WHO-principles of acute pediatric pain management • Discuss the concept of multimodal analgesia • Calculate morphine requirements for a child in severe pain
M11: Opioid Selection and Opioid Rotation	• Review opioids commonly used in pediatric palliative care ○ Pharmacology ○ Routes of administration ○ Common adverse effects • Review opioids not recommended for pediatric use • Practice opioid rotation in a case example
M12: Management of Neuropathic Pain Management and Adjuvant Analgesia	• Appreciate the high prevalence of neuropathic pain in pediatric palliative care • Define neuropathic pain and describe main causes in pediatric patients • Discuss the role of opioids in neuropathic pain management • Develop a step-by-step treatment approach for neuropathic pain, including pharmacologic (opioids, non-opioids, and adjuvants), procedural, and integrative medicine approaches

(*Continued*)

Table 1
Continued

Module Title	Objectives
M13: Procedural Pain Management Strategies	• Describe the evidence for the importance of managing procedural pain • Review the four essential pain management strategies for needle procedures • Identify pharmacologic agents including dose, route of administration, monitoring, and adverse effects • Identify behavioral and integrative strategies that facilitate coping with procedures
M14: Chronic Complex Pain[a]	• Discuss the prevalence of chronic pain and underlying pathophysiology in children • Appreciate that different chronic pain syndromes are often considered manifestations of an underlying vulnerability rather than separate disorder • Review the limited role for pharmacotherapy in children with chronic pain • Stress the importance of a rehabilitative, interdisciplinary team approach in managing chronic pain • Discuss management of children who have both acute pain, such as vaso-occlusive crisis in sickle-cell disease, and chronic daily musculoskeletal pain
M15: Management of Gastrointestinal Symptoms	• State the spectrum and impact of gastrointestinal symptoms • Recognize pathophysiology involved in nausea and vomiting, and learn to prescribe appropriate antiemetic therapy • Diagnose and treat diarrhea and constipation • Explain the diagnosis and treatment of anorexia-cachexia syndrome • Discuss weight changes and loss of appetite with caregivers
M16: Management of Respiratory Symptoms	• Appreciate the high prevalence of dyspnea, excess respiratory secretions and cough in pediatric palliative care and often inadequate treatment by clinicians • Discuss pathophysiology of common respiratory symptom in pediatric palliative care • Describe the role of opioids as a first-line agent in dyspnea • Develop a step-by-step approach in managing dyspnea and other respiratory symptoms
M17: Management of Emotional and Behavioral Symptoms	• Describe approaches to emotional and behavioral aspects of palliative care • Discuss "phenotypes" of psychological and behavioral pathology in seriously ill children • Review the assessment and potential treatments for each phenotype • Identify thresholds for referral to mental health clinicians
M18: Management of Neurological Symptoms	• Review neurological complications of children with serious illnesses, including advanced pediatric hematology/oncology conditions, and treatment strategies • Identify causes of pain behaviors in children with neurological impairment • Develop step-by-step approach to manage distressing neurological symptoms in pediatric palliative care
M19: Management of Refractory Distress	• Describe persistent myths about palliative sedation • Explain the circumstances under which palliative sedation may be indicated • Describe recommended dosing for palliative sedation in children • Review the potential alternatives to palliative sedation
M20: Preparation for Imminent Death	• Define the end-of-life period • Describe the tasks necessary for managing pain and distress at end of life • Identify important issues that require careful communication and planning • Describe the essential components of good care at the very end of life
M21: Integrative Medicine	• Describe how integrative medicine strategies can enhance care for children with life-threatening conditions. • Practice an relaxation and mental imagery exercise. • Review importance of safe and effective integrative medicine modalities to improve pain and symptom management as well as quality of life for seriously ill children

(*Continued*)

Table 1
Continued

Module Title	Objectives
M22: Introducing Quality Improvement in PPC	• Discuss why quality improvement methodology is an important approach for integrating pediatric palliative care into services • Describe the basic concepts of quality improvement approaches • Describe the first steps to improve quality • Complete a performance improvement project
M23: Teaching Pain and Symptom Management	• Describe the goals of education • Explain how adults learn best • Use personal style and presentation skills to make teaching more effective • Cope with "challenging" participants • Experience different presentation modalities
M24: Methadone	• Review advantages and disadvantages of methadone use • Evaluate potential adverse effects of methadone • Explain difference of half-life compared with other opioids • Practice opioid rotation to methadone

EPEC = Education in Palliative and End-of-Life Care; PPC = pediatric palliative care; FCC = family-centered care; WHO = World Health Organization.
[a]Included M24: Methadone in the online version until 2018.

modules, four of them addressing pain and symptom management.[32] EPEC and EPEC-Pediatrics are designed to train non-palliative care specialists in basic palliative care competencies, referred to in the literature as "primary palliative care."[24,33]

In late 2010, an EPEC-Pediatrics Advisory Group of 11 PPC specialists, including two bereaved parents, was established to oversee curriculum development and writing (Appendix Table 1). The writers group consisted of PPC specialists, physicians, advanced practice nurses, nurses, social workers, and other members of interdisciplinary PPC teams. After a consensus process on importance of inclusion, 23 modules were eventually chosen for the curriculum (Table 1) with a 24th module (Methadone) split off as a separate module in 2016. The consensus was that assessment and advanced treatment of distressing symptoms of children with serious illness was underemphasized in existing curricula and thus became a significant focus of EPEC-Pediatrics. Compared with four adult EPEC modules, in the pediatric version, 12 modules (or 50%) address pain and symptom management, with the remainder covering the "nuts-and-bolts" of PPC (Table 1). In addition to the core editorial team, there were 27 additional writers producing the curriculum content (Appendix Table 1), which included: 1) 24 PowerPoint/Keynote presentations plus 2) detailed teaching guides for each module, with 3) 18 of those also available online for self-study (Table 1). In addition to text and slide presentations, 4) professional quality video training vignettes were filmed, and PPC experts were interviewed for development of so-called trigger tapes. Each module also includes relevant psychosocial content, emphasizing family-centered care practice and sensitivity.

Curriculum Content

EPEC-Pediatrics was created for delivery in a combination of online learning and in-person conference sessions.[5] Online learning modules were made available to decrease travel costs and offer a more flexible schedule. Each presentation of the curriculum included 18 (+1 split off) self-study online modules and 1.5–2 days of in-person conference training (five to eight modules). Modules chosen for in-person instruction included those that focused on interactional skills and that allowed us to demonstrate innovative teaching techniques.

Teaching How to Teach: Hook Attitude, Knowledge, and Skill

A common misconception in medical teaching appears to be that presenting "knowledge" (e.g., displaying a large number of PowerPoint slides) alone will lead to behavior change (e.g., a physician will decide to administer morphine to a child with terminal dyspnea after the lecture). Unfortunately, this approach has not been shown to be effective,[34–36] and Dixon postulated that to change clinicians' behavior, and thereby patient outcomes, one needs to address "attitudes" and "skills" in addition to "knowledge."[37] Therefore, EPEC-Pediatrics has been designed to help participants focus on teaching skills that include how to engage audiences (such as a "hook" or "reason to learn" at the start of a presentation) and how to address objectives that include attitudes, knowledge, and skills.

EPEC-Pediatrics Creates Trainers and Master Facilitators

True to the NCI/NIH funding, the initial emphasis of EPEC-Pediatrics was on pediatric hematology/

oncology physicians and nurse practitioners, later opening to pediatric clinicians from all other fields and specialties. The curriculum teaches interdisciplinary pediatric clinicians and creates Trainers who are equipped to teach colleagues. These Trainers teach end-users, interdisciplinary participants who receive education offered by Trainers in the competencies of general PPC. This Train-the-Trainer approach allows the Trainers (pediatric clinicians) access to training materials (including 24 PowerPoint slides, videos, cases, role plays, text, and Trainer's notes—teaching guides for Trainers who will be teaching the curriculum) for all modules, once the full course is completed.

MFs are EPEC-Pediatrics Trainers, who, following a designated Professional Development Workshop (PDW) of adult teaching techniques, successfully provided supervised teaching at one or several Train-the-Trainer conferences. The PDW is a one-day conference that is designed to give specific practice and feedback on teaching techniques emphasizing interactive lectures, case-based teaching, and role play.

The key teaching modalities both Trainers and MFs experience and practice during EPEC-Pediatrics are as follows: 1) interactive lecture, 2) role play, and 3) case-based teaching. We strongly discourage the use of too many slides and encourage use of small group discussion, and/or facilitated discussion with all participants, using flip charts, and other interactional strategies. In this way, the educational materials and strategy can be adapted to the needs of the audience in real time.

The EPEC-Pediatrics training materials are designed as "accordion modules." Specifically, each of the 24 modules generally contains more material that can be taught in one hour, encouraging the Trainer to select relevant content for their specific audience. Trainers receive the explicit permission to modify the EPEC-Pediatrics slides or material for their individual teaching needs and we emphasize and practice the following established EPEC teaching components[28]:

- Consider starting with a "Needs Assessment." Engage the audience—what they would like you to cover in your teaching.
- Consider using a "Hook." Identifying a "hook" or "tension-point" for the educational program can be a powerful lead-in. This might be a compelling patient story that underscores the need for change, a video, a review of common myths and misconceptions, statistics about inadequate pain control, or the incidence of suffering in certain situations. The goal is to heighten the participants' awareness and motivation for the need to change, and as such learning.
- Address "Attitudes"/Barriers/Myths/Misconceptions and how to overcome them. For example, identify and address common myths preventing opioid prescription for children with severe pain.
- Provide "Knowledge." For example, "Discuss the four World Health Organization principles of acute pediatric pain management." Make the presentation interactive with cases, videos, etc., and reduce the number of slides. Although it is unclear what the maximum attention span of professional audiences is,[38] we recommend to interrupt a lecture at least every eight to 10 minutes (e.g., with a video, interactive session, case, etc.) to maintain the audience's interest.[39]
- Teach a "Skill." For example, "Practice morphine prescription in small groups using a case example."

EPEC-Pediatrics Dissemination Model

Our dissemination model included the following three phases: 1) the adaptation of the EPEC core curriculum to fit the needs of infants, children, and adolescents; 2) the creation of a core faculty of MFs to create Trainers; and 3) the evolution of the program design to fit the needs of new educational delivery systems and health care settings.

The primary intended audience was initially physicians and nurse practitioners in pediatric hematology and oncology. However, we also emphasized PPC issues for children with non-malignant diseases and made the content relevant for other interdisciplinary team members. The goal of this model is maximal dissemination of primary PPC content to non-palliative care specialists through a variety of settings and delivery methods.

We started by beta-testing the face-to-face Train-the-Trainer conference in Boston, MA, in 2012. Using the detailed feedback of the Trainers and MFs, the EPEC-Pediatrics program (http://epec.net/epec_pediatrics.php) has been continuously modified and refined throughout the grant funding period, which included seven NIH/NCI-funded Train-the-Trainer conferences, as well as eight conferences, which were offered outside of the funded program (Fig. 1 and Table 3). EPEC-Pediatrics offers three levels of training (Table 2) and represents a virtual college (Fig. 2).

To teach additional core faculty MFs after the initial pediatric MFs were trained, we created a designated pediatric PDW. This consisted of one day of intensive teaching and feedback about adult learning, including sessions on giving interactive lectures, facilitating small groups and case studies, and facilitating role play. After completion of the PDW, MF candidates were invited to co-facilitate at a subsequent EPEC-

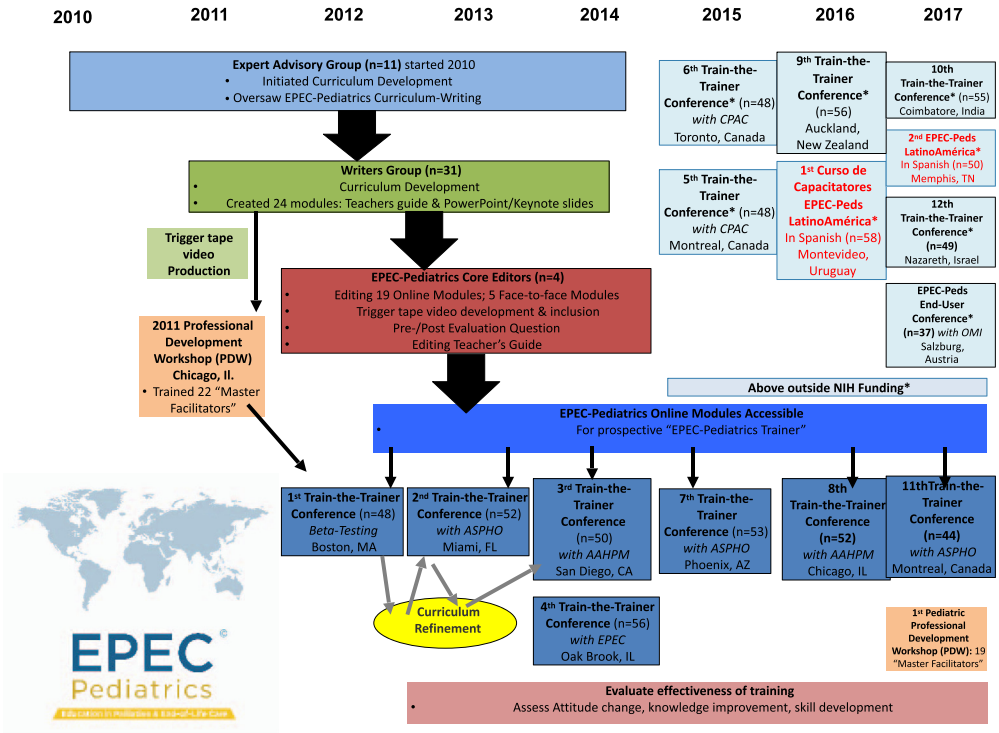

Fig. 1. Development of the EPEC-Pediatrics curriculum and dissemination during the NIH/NCI grant period 2010–2017. NIH/NCI = National Institutes of Health/National Cancer Institute; CPAC = Canadian Partnership Against Cancer; ASPHO = American Society of Pediatric Hematology/Oncology; AAHPM = American Academy of Hospice and Palliative Medicine.

Pediatrics conference and receive further guidance and feedback. We believe that this type of development and feedback of our facilitators is critical to the quality of instruction.

Additional funding led to adapting the curriculum for Latin America and Canada, including Spanish and French translations, as well as teaching in several foreign countries. EPEC-Pediatrics LatinoAmerica[40]

Table 2
EPEC-Pediatrics: Three Levels of Training

		Description	On Completion
Level 1	"End-user" Conference/Training	• PPC Training (custom made 1–5 days) • Participants to learn through interactive lectures, case-examples, role-play • Participants NOT expected to teach curriculum material • Taught by EPEC-Pediatrics Trainers (and/or Master Facilitators)	Increased knowledge about primary PPC
Level 2	Train-the-Trainer Conference	• Completion of all 19 Online Modules • Participation in "Become an EPEC-Pediatric Trainer Conference" (1½–3 days) • Learn how to teach health care professionals • Use interactive teaching styles skillfully • "Trainers" receive curriculum material, are encouraged and expected to teach	Become an EPEC-Pediatrics Trainer
Level 3	Professional Development Workshop	• For EPEC-Pediatrics Trainers only • Small-group workshop • Theory & practice of adult learning and clinical practice improvement in teaching pediatric pain and palliative care • Master best presentation techniques • Supervised teaching at Train-the-Trainer Conference with feedback	Become a candidate for EPEC-Pediatrics Master Facilitator

EPEC = Education in Palliative and End-of-Life Care; PPC = pediatric palliative care.

Table 3
Participant Demographics for the Seven EPEC-Pediatrics "Train-the-Trainer Courses" Offered Within NIH/NCI Grant

Master facilitators[a]	23
Trainers (participants)	348
Medical specialty	
Hematology/Oncology	146 (42%)
Other	202 (58%)
Clinical role	
Physician	261 (75%)
Nurse/NP/PA	77 (22%)
Other (e.g., social worker)	10 (3%)
Geographic representation by country	
U.S.	267 (77%)
Canada	29 (8%)
Other[b]	52 (15%)

EPEC = Education in Palliative and End-of-Life Care; NIH/NCI = National Institutes of Health/National Cancer Institute; NP = nurse practitioner; PA = physician assistant.
Boston (2012), Miami (2013), San Diego (2014), Oak Brook (2014), Phoenix (2015), Chicago (2016), and Montreal (2017).
[a]Four Master Facilitators are part of the core team.
[b]Other countries represented include: Argentina (3), Australia (4), Brazil (1), Colombia (1), Costa Rica (3), Denmark (4), Dominican Republic (1), Egypt (1), England (1), Guatemala (2), India (3), Israel (1), Japan (1), Jordan (1), Kuwait (2), Mexico (3), New Zealand (1), Puerto Rico (5), Qatar (1), Russia (2), Saudi Arabia (1), Scotland (2), South Africa (1), South Korea (1), Sweden (1), Turkey (1), Ukraine (2), Uruguay (1), and Venezuela (1).

began with the training of eight South American MFs and an initial Train-the-Trainer conference with 58 participants from seven countries. Another satellite project was funded by the Canadian Partnership Against Cancer in 2014 with CAN$ 950,000 and developed in collaboration with seven Canadian provincial Ministries of Health, Family Advocacy: Childhood Cancer Canada Foundation, Ontario Parents Advocating for Children with Cancer; Pediatric Oncology: Atlantic Provinces Pediatric Hematology/Oncology Network, C17 Council, Canadian Paediatric Brain Tumor Consortium, and the Pediatric Oncology Group of Ontario. The overall project, "Enhancing the Quality of Palliative and End-of-Life Care for Children with Cancer" trained regional teams from 15 Canadian children's hospitals and involved implementation of a quality improvement (QI) project that resulted in training of four Canadian MFs. The 96 participants of two regional conferences trained more than 3500 end-users in all regions of Canada.[41] Countries outside the U.S. in which EPEC-Pediatrics has been taught include: Australia, Austria (which included training clinicians from seven Eastern European countries), Canada (×3), India (×2), Israel (for Palestinian and Israeli clinicians), Malaysia, and New Zealand. Between 2012 and March 2019, there were a total of 867 EPEC-Pediatrics Trainers and 75 MFs from 58 countries representing all six continents (Fig. 3) trained as a result of conducting a total of 17 Train-the-Trainer conferences and three PDWs.

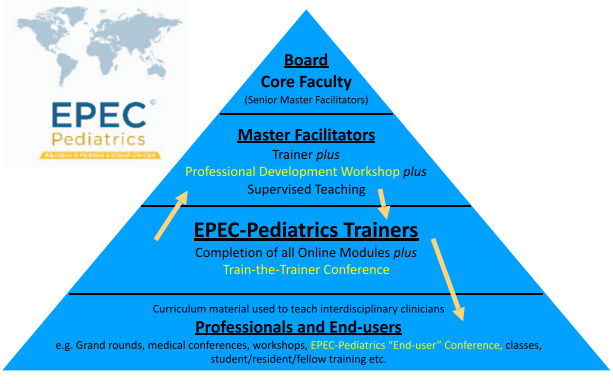

Fig. 2. EPEC-Pediatrics—A virtual college. EPEC = Education in Palliative and End-of-Life Care.

Number of End-Users Trained

Results from Canada, where 72 EPEC-Pediatrics Trainers taught 3475 end-users[42] and from Australia, where 54 Trainers taught more than 6000 end-users [*personal communication*] suggest that between 48 and 111 end-users might have been educated by an individual EPEC-Pediatrics Trainer. As such, within the NIH grant, we trained 346 Trainers, reaching an estimated 16,600–38,400 end-users, and a total of so far 867 Trainers (May 2019), possibly reaching approximately 41,000–96,000 end-users.

Part 2: NIH/NCI Grant-Funded Conferences

This section of this article describes the EPEC-Pediatrics program training outcomes for the seven Train-the-Trainer conferences funded through the NIH/NCI grant period 2012–2017, including knowledge, skills, attitudes, and participant evaluations. We also describe current and anticipated post-grant training and program sustainability plans.

Participant Characteristics

Within NIH/NCI grant, there were 7 Train-the-Trainer conferences held across the U.S. and Canada from 2012 to 2017, with 348 individual participants and 23 MFs trained (Table 3). Each conference was attended by between 44 and 54 participants and each conference was held over 1.5–2 days.

Training Outcomes—Knowledge, Skills, Attitudes, and Program Evaluation

Introduction

Of the 24 training modules, 19 were made available on-line and five of the modules were designed to be exclusively offered in the face-to-face setting: Teaching with EPEC-Pediatrics in the face-to-face setting (M9), Teaching Through Interactive Lecture (M23), Team Collaboration and Effectiveness (M6), Self-Care for Professionals (M5), and Communication

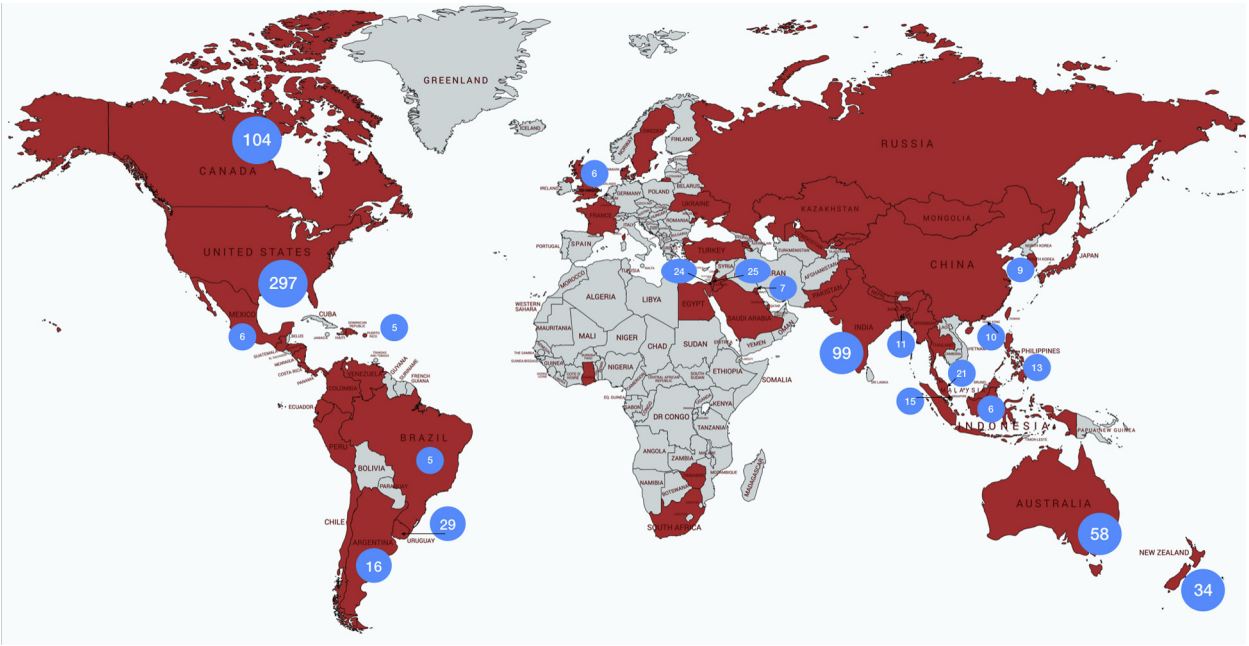

Fig. 3. EPEC-Pediatrics Train-the-Trainers Participants 2012–March 2019: 867 Trainers plus 75 Master Facilitators from 58 countries and territories.

and Planning (M7). There were no online modules available for the initial beta-testers in Boston 2012, and the remaining 305 (88%) of the 348 NIH/NCI funded face-to-face conference participants completed training modules online.

Knowledge

Knowledge gained was assessed after completion of each online module with the question: "I have obtained new information (knowledge) as a result of completing this course [module]." The total percentage of Trainers reporting that they obtained new knowledge (yes/no) across all online modules was 84.3% (range from 96% for Neuropathic Pain to 67% for Family-Centered Care). See Table 4 and Appendix Table 3 for the assessment of each module.

Skills

Two online module evaluation items assessed Trainers' perceptions of skills obtained, by module (yes/no): 1) "This educational activity will impact my competency (skills/abilities/strategies gained from the new information)" and 2) "This educational activity will impact my performance (implementing the new skills/abilities/strategies)." Overall, agreement with the first item was a mean of 86.2% across all modules. Online modules with the highest agreement with the first item about competency were opioid selection and rotation ($n = 164$, 93.7%) and neuropathic pain ($n = 222$, 94.9%). For the second item about skills implementation, the overall agreement with the statement across all modules was 83.1%.

Attitude/Behavior Change

Trainer attitudes were assessed with one online training question that was asked after completion of each module: "This module is going to change my practice on return to my institution (Yes/No)." The percentage of overall agreement (across modules) was 85.1%. Open-ended feedback for the top-rated pain and symptom-focused modules and the top-rated psychosocial modules can be seen in Table 5.

Face-to-Face Program Evaluation

Evaluations were used to help refine the program and were given for each module presented and for the overall conference. The evaluations included questions about meeting the module objectives, if the presentation(s) will likely affect change, and how to improve the conference in the future. The percentage of Trainers reporting new knowledge and skills gained across all modules taught was 98%. Because the face-to-face individual module evaluations were offered by different MFs across conferences and scores were influenced by MF teaching style, etc., findings are not comparable across conferences and not reported here.

Overall Face-to-Face Conference Feedback

Trainers were asked to complete a summary evaluation after the face-to-face training conferences. In

Table 4
Training Evaluation of Online Modules During NIH Grant Funding (% Questions Answered With "Yes")

	I Have Obtained New Information (Knowledge) as a Result of Completing This Course	This Educational Activity Will Impact My Competency (Skills/Abilities/Strategies Gained From the New Information)	This Educational Activity Will Impact My Performance (Implementing the New Skills/Abilities/Strategies)	The Skills/Abilities/Strategies I Have Obtained at This Activity Potentially Will Affect My Patient's Outcomes?
11 Advanced pain & symptom management modules[a] (mean $n = 179$ [range 127–244] responses)	89%	89.6%	85.4%	89.6%
7 "Nuts & Bolt" PPC modules (mean $n = 193$ [range 133–256] responses)	77.1%	80.4%	78.6%	81.6%
All 18 online modules	84.4%	86%	82.7%	**86.5%**

NIH = National Institutes of Health; PPC = pediatric palliative care.
[a]The online Module 14 "Chronic Complex Pain" has been split into two modules: M14 Chronic Complex Pain and M24 Methadone.

addition to questions about knowledge, attitudes and skills, the overall face-to-face evaluations included questions asking participants to describe strengths and weaknesses of the conference, as well as suggestions for improvement. Common themes from a descriptive thematic analysis of the three most recent conferences held during the grant funding period were as follows. Overall feedback was very positive, with participants expressing appreciation for the opportunity. Participants felt that observing different MF teaching styles was helpful and the conference provided a good opportunity to network with peers. Several participants felt the two-day format was too short and suggested offering a longer face-to-face

Table 5
Themes Identified During Open-Ended Evaluations After Online Module Completion for the Top-Rated Online Modules

	Change in Practice	Most Valuable Topic	Skills/Abilities Gained
Pain & Symptom Modules			
Neuropathic pain (88%)	Efforts to improve multifaceted approach to neuropathic pain; non-pharmacological approaches to pain; step-wise process	Eight-step approach; adjuvant therapies (ketamine)	Better assessment of neuropathic pain; improved knowledge of neuropathic pain and treatment options available; better use of adjuvant therapies
Acute pain management (85%)	Better tailoring of opioids to meet individual patient needs; "We have to rearrange all pain control approaches in our institution"; previous under-dosing	Dosing/titration strategies; WHO guidelines	Teach opioids differently; better titration of meds; better pain management skills
Chronic/complex pain (84%)	Use of methadone; do not use opioids for chronic pain	Use of methadone; chronic pain approach	Being able to recognize chronic pain issues and how to approach them; using the four S's to treat chronic pain
Psychosocial Modules			
Child development (70%)	Better/appropriate ways to interact with children and families based on child development	Examples of how children in different developmental stages cope with serious illness	Communication/Strategy
Grief and bereavement (70%)	Anticipatory grief guidance (increased awareness of the need for anticipatory guidance regarding grief); efforts to improve team follow-up after death; improve bereavement resources	Children's developmental expectations regarding death; prolonged grief	More tools and knowledge when talking to families and patients; better follow-up after death

four S's = school, sleep, social, sports; WHO = World Health Organization.

course in the future to an expanded audience (i.e., not only pediatric clinical providers).

Satellite Programs

Several satellite programs have developed from EPEC-Pediatrics, including "Enhancing the Quality of Palliative and End-of-Life Care for Children with Cancer" funded by Canadian Partnership Against Cancer, and "EPEC-Pediatrico LatinoAmerica." In Canada, EPEC regional teams of three to six health professionals based at 15 pediatric oncology programs in Canada became EPEC-Pediatrics Trainers who then taught the curriculum to health professionals and implemented QI projects. Seventy-two Trainers taught 3475 learners; the majority (96.7%) agreed that their PPC knowledge improved. In addition, 10 of 15 sites achieved practice change QI goals.[42] All slides have been translated into French.

EPEC-Pediatrics LatinoAmérica trained eight Latin-American physicians as EPEC-Trainers and MFs during the first Train-the-Trainer Conference 2014–2016 on Sept 6–7, 2015 (Montevideo, Uruguay). The "first Train-the-Trainer Conference (Curso de Capacitatores EPEC-Peds LatinoAmérica)" included 58 participants and MFs from Argentina, Brazil, Dominican Republic, Ecuador, Guatemala, Mexico, and Uruguay. The second Spanish-speaking conference will be held in November 2019 in Argentina.

In addition, we are currently preparing for the development of an EPEC-Pediatrics International program tailored to the needs of low- to low-medium income countries in an effort to reach more Trainers and end-users in underserved locations across the globe. Several conferences in India, Malaysia, New Zealand, and Australia were tailored to increase the foothold of PPC Trainers in South-East Asia and Oceania.

Discussion

This article describes the development and dissemination of the to date most comprehensive PPC curriculum and education dissemination project worldwide: EPEC-Pediatrics. Between 2012 and 2019, 17 conferences were held and a total of 867 EPEC-Pediatrics Trainers and 75 MFs from 58 countries were trained. Participants overwhelmingly reported improvements in their PPC knowledge, attitude and skills, teaching skills, and by a large majority anticipated positive clinical changes in patient care of children with serious illness in their home institution as a result. An estimated 41,000–96,000 participants (end-users) have been educated by EPEC-Pediatric Trainers worldwide so far. Demand for this training remains high. After the completion of the NIH/NCI funding in 2017, EPEC-Pediatrics offered six new "Train-the-Trainer Conferences" in India, Argentina, Australia, Italy, and the U.S. (×2) in 2019 alone. In addition, EPEC-Pediatrics has led to other grants and two adaptations (e.g., Canada, Latin America) with a Global EPEC-Pediatrics for low-medium income countries in development.

In our experience, it has become clear that there is a great need for similar training for psychosocial clinicians working in pediatrics. It is also important to note that PPC is by definition an inter-professional practice. Therefore, steps are being undertaken to enhance the psychosocial content in EPEC-Pediatrics to enable training for psychosocial clinicians and to allow inter-professional teaching in a more robust fashion going forward.

Initially, the goal in our NCI grant submission was to train at least 190 Trainers (participants) over a five-year period through EPEC-Pediatrics. This goal was exceeded, with a total of 348 Trainers completing the EPEC-Pediatrics program through NIH/NCI grant funding 2012–2017. An additional 519 Trainers were educated outside the grant (through May 2019). Trainers, who successfully completed all online training modules and participated in the Face-to-Face Conference, were granted access to all EPEC-Pediatrics training materials so that they could conduct training with staff at their own institutions or regions, and they received Continuing Education credits on successful completion of the online modules and a face-to-face training conference. "Trigger-tape" educational videos and a teaching handbook for each module were included. We are currently conducting a survey of all 867 EPEC-Pediatrics Trainers (participants of Train-the-Trainer conference) and the 75 MFs to evaluate in detail how many of them have used the curriculum for teaching, clinical or quality improvement, and which material they have used in what way.

Since the end of the NIH grant-funding period in 2017, EPEC-Pediatrics has remained viable and self-sustaining. This has been accomplished through non-profit cost-recovery from registration fees and very little organizational overhead, with eight additional conferences held after 2017 (see Appendix Table 2). At the time this article was submitted, organization for conferences in Memphis, TN (September 2019); Minneapolis, MN (October 2019); Rome, Italy (November 2019); and Buenos Aires, Argentina (November 2019) are underway.

Hauser et al.[28] described that in their 2nd five years of active development, teaching, and dissemination of adult EPEC, they had trained more than 1000 Trainers and more than 74,000 reported end-users via Trainers' training efforts and online learning. The authors were

aware that they were unable to document end-users from programs that do not track their outreach, those who did not respond to their survey of trainers, or those who use the curriculum without contacting them.[28] Estimating pediatric data is equally difficult: We have estimated that conservatively more than 41,000 end-users were trained by EPEC-Pediatrics trainer worldwide; but, as mentioned earlier, we are currently conducting a detailed survey to further characterize these data.

We believe that EPEC-Pediatrics fits well within an established framework of levels of PPC training: primary, advanced, and subspecialty training.[43] At "Level 2: Advanced Primary PPC/Introductory Subspecialty PPC" EPEC-Pediatrics has now been developed as the most comprehensive PPC curriculum and dissemination "Train-the-Trainer" project worldwide. The curriculum originally had not been designed to train PPC specialists, but rather to give clinicians comprehensive tools to teach core PPC to interdisciplinary teams and promote best PPC practices by hematologists/oncologists and other pediatric specialists. However, since its inception, we received feedback that is also used for training of PPC specialists, both inside and outside designated fellowship programs.

Next Steps for 2019–2020

In addition to offering six EPEC-Pediatrics conferences and two PDWs on four continents (Table 3), we were successful in obtaining additional grant funding. This came from The Milbank Foundation, United States Cancer Pain Relief Committee, and The Mayday Fund. This funding will allow for an update of all 24 modules (PowerPoints, teaching guides, and update of 24 online modules), organizing the conference in Argentina as well as offering a three-day face-to-face conference in October 2019 and a four-day face-to-face conference in 2020 to evaluate difference in online versus face-to-face teaching.

Summary

Since its inception in 2012, EPEC-Pediatrics has developed into the most comprehensive PPC curriculum and dissemination program worldwide. More than 800 clinicians in all six continents have become Trainers and MFs and we estimate that more than 38,000 end-users have been trained. In addition, a Spanish-speaking version is available and all slides have been translated into French. The 867 Trainers reported not only improvements in their personal PPC knowledge, attitude and skills, but also in their teaching skills and anticipated clinical improvements in patient care of children with serious illness in their home institution as a result. EPEC-Pediatrics is a state-of-the-art educational program that has, and will continue to a train a global network of health care professionals who are in turn positioned to train others in their communities to provide evidence-based care for children with palliative care needs and their families. The curriculum is highly adaptable for local settings, and a local faculty of senior MFs have been trained in several regions (e.g., in South America, Canada, South-East Asia, Australia/New Zealand, India, and in November 2019 beginning in Europe) to ensure ongoing training with little or no reliance on the U.S.-based core MFs.

Disclosures and Acknowledgments

The authors wish to thank the members of the EPEC-Pediatrics Advisory Council, the EPEC Pediatrics Writers, and all EPEC-Pediatrics Master Facilitators. Special thanks to Linda Emanuel as well as Katie McGuire, Lexie Goertzen, Derek Jarvis, Elisa Roman, Veronica Roman, Kim Honcharenko, and Cheryl Puumala for their strong support of EPCE-Pediatrics.

Funding from National Institutes of Health (NIH)/National Cancer Institute (NCI) (R25 CA151000). NIH grant #R25 CA151000-01.

The authors declare no conflicts of interest.

References

1. Connor SR, Downing J, Marston J. Estimating the global need for palliative care for children: a cross-sectional analysis. J Pain Symptom Manage 2017;53:171–177.

2. Murphy SL, Mathews TJ, Martin JA, Minkovitz CS, Strobino DM. Annual summary of vital statistics: 2013-2014. Pediatrics 2017;139.

3. American Cancer Society, 2018: Facts & Figures. Atlanta, GA. Available from https://www.cancer.org/cancer/cancer-in-children/key-statistics.html. Accessed July 3, 2019.

4. National Vital Statistics Reports, Deaths: Final data for 2015, 2017, Vol. 66, Washington, D.C.: National Academies Press. Available from https://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66_06.pdf. Accessed July 3, 2019.

5. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. N Engl J Med 2000;342:326–333.

6. Hechler T, Blankenburg M, Friedrichsdorf SJ, et al. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. Klinische Padiatrie 2008;220:166–174.

7. Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? J Clin Oncol 2008;26:1717–1723.

8. Feudtner C, Kang TI, Hexem KR, et al. Pediatric palliative care patients: a prospective multicenter cohort study. Pediatrics 2011;127:1094–1101.

9. Friedrichsdorf SJ, Postier A, Dreyfus J, et al. Improved quality of life at end of life related to home-based palliative care in children with cancer. J Palliat Med 2015;18:143–150.

10. Rosenberg AR, Orellana L, Ullrich C, et al. Quality of life in children with advanced cancer: a report from the PediQUEST study. J Pain Symptom Manage 2016;52:243–253.

11. Friedrichsdorf SJ, Postier AC, Andrews GS, et al. Pain reporting and analgesia management in 270 children with a progressive neurologic, metabolic or chromosomally based condition with impairment of the central nervous system: cross-sectional, baseline results from an observational, longitudinal study. J Pain Res 2017;10:1841–1852.

12. Osenga K, Postier A, Dreyfus J, et al. A comparison of circumstances at the end of life in a hospital setting for children with palliative care involvement versus those without. J Pain Symptom Manage 2016;52:673–680.

13. Wolfe J, Orellana L, Ullrich C, et al. Symptoms and distress in children with advanced cancer: prospective patient-reported outcomes from the PediQUEST study. J Clin Oncol 2015;33:1928–1935.

14. Kassam A, Skiadaresis J, Alexander S, Wolfe J. Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. Pediatr Blood Cancer 2015;62:1409–1413.

15. Ananth P, Melvin P, Feudtner C, Wolfe J, Berry JG. Hospital use in the last year of life for children with life-threatening complex chronic conditions. Pediatrics 2015;136:938–946.

16. Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. J Palliat Med 2014;17:183–188.

17. Committee on Approaching Death. Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, D.C.: The National Academies Press., 2015.

18. Friedrichsdorf SJ. Contemporary pediatric palliative care: myths and barriers to integration into clinical care. Curr Pediatr Rev 2017;13:8–12.

19. Szymczak JE, Schall T, Hill DL, et al. Pediatric oncology providers' perceptions of a palliative care service: the influence of emotional esteem and emotional labor. J Pain Symptom Manage 2018;55:1260–1268.

20. Himelstein BP, Kane RJ. Appendix G: Education in pediatric palliative care. In: Field MJ, Behrman RJ, eds. When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. Washington, D.C: Institute of Medicine (US) Committee on Palliative and End-of-Life Care for Children and Their Families. National Academies Press (US), 2003.

21. Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board; Foley KM, Gelband H, eds.Washington, D.C.: National Academies Press (US); 2001.

22. Feudtner C, Womer J, Augustin R, et al. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. Pediatrics 2013;132:1063–1070.

23. America Academy for Hospice and Palliative Medicine (AAHPM). Clinical Training: Hospice and Palliative Medicine Fellowship Training. 2018. Available from http://aahpm.org/career/clinical-training#fellowship-directory. Accessed July 3, 2019.

24. Quill TE, Abernethy AP. Generalist plus specialist palliative care–creating a more sustainable model. N Engl J Med 2013;368:1173–1175.

25. Robinson K, Sutton S, von Gunten CF, et al. Assessment of the education for physicians on end-of-life care (EPEC) project. J Palliat Med 2004;7:637–645.

26. VanGeest JB. Process evaluation of an educational intervention to improve end-of-life care: the education for physicians on end-of-life care (EPEC) program. Am J Hosp Palliat Care 2001;18:233–238.

27. Gisondi MA, Lu DW, Yen M, et al. Adaptation of EPEC-EM curriculum in a residency with asynchronous learning. West J Emerg Med 2010;11:491–499.

28. Hauser JM, Preodor M, Roman E, Jarvis DM, Emanuel L. The evolution and dissemination of the education in palliative and end-of-life care program. J Palliat Med 2015;18:765–770.

29. Malloy P, Sumner E, Virani R, Ferrell B. End-of-life nursing education consortium for pediatric palliative care (ELNEC-PPC). MCN Am J Matern Child Nurs 2007;32:298–302. quiz 303-4.

30. Browning DM, Solomon MZ, Initiative for Pediatric Palliative Care Investigator Team. The initiative for pediatric palliative care: an interdisciplinary educational approach for healthcare professionals. J Pediatr Nurs 2005;20:326–334.

31. National Hospice and Palliative Care Organization (NHPCO). Children's International Project on Palliative/Hospice Services (ChIPPS). 2001. Available from https://promotingexcellence.growthhouse.org/chipps/compendium.html. Accessed July 3, 2019.

32. Northwestern University, Chicago, IL. EPEC Core Curriculum. 2018. Available from http://bioethics.northwestern.edu/programs/epec/curricula/index.html. Accessed July 3, 2019.

33. von Gunten CF. Secondary and tertiary palliative care in US hospitals. JAMA 2002;287:875–881.

34. Gupta DM, Boland RJ Jr, Aron DC. The physician's experience of changing clinical practice: a struggle to unlearn. Implement Sci 2017;12:28.

35. Morris ZS, Wooding S, Grant J. The answer is 17 years, what is the question: understanding time lags in translational research. J R Soc Med 2011;104:510–520.

36. Mostofian F, Ruban C, Simunovic N, Bhandari M. Changing physician behavior: what works? Am J Manag Care 2015;21:75–84.

37. Dixon J. Evaluation criteria in studies of continuing education in the health professions: a critical review and a suggested strategy. Eval Health Prof 1978;1:47–65.

38. Bradbury NA. Attention span during lectures: 8 seconds, 10 minutes, or more? Adv Physiol Educ 2016;40:509–513.

39. Miller CJ, McNear J, Metz MJ. A comparison of traditional and engaging lecture methods in a large, professional-level course. Adv Physiol Educ 2013;37:347–355.

40. Instituto de Effectividad Clinica y Sanitaria A. Curso: EPEC-Pediátrico Latinoamericano. 2019. Available from https://www.iecs.org.ar/portfolio/curso-epec-pediatrico-latinoamericano/. Accessed July 3, 2019.

41. Widger K, Friedrichsdorf S, Wolfe J, et al. Protocol: evaluating the impact of a nation-wide train-the-trainer educational initiative to enhance the quality of palliative care for children with cancer. BMC Palliat Care 2016;15:12.

42. Widger K, Wolfe J, Friedrichsdorf S, et al. National impact of the EPEC-pediatrics enhanced train-the-trainer model for delivering education on pediatric palliative care. J Palliat Med 2018;21:1249–1256.

43. Friedrichsdorf SJ. From denial to palliactive - practical steps for developing a PPC program: training. In: 4th Congress on Paediatric Palliative Care - a Global Gathering, Rome, Italy. October 24-27, 2018 2018.

Appendix

Appendix Table 1
EPEC-Pediatrics Investigators, Advisory Group, and Writers Group

(A) Core Investigator Team and Curriculum Editors
- Stefan J. Friedrichsdorf[a], MD (PI), Children's Hospitals and Clinics of Minnesota, Minneapolis, MN; University of Minnesota Medical School, Minneapolis, MN
- Joanne Wolfe[a], MD, MPH (CI), Dana-Farber Cancer Institute, Boston Children's Hospital, Boston, MA
- Joshua Hauser, MD (CI), Department of Medicine, Northwestern Feinberg School of Medicine, and Jesse Brown VA Medical Center, Chicago, IL
- Stacy Remke[a], MSW, LICSW (CI), Children's Hospitals and Clinics of Minnesota, University of Minnesota School of Social Work, St. Paul, MN
- Linda Emanuel, MD (CI), Buehler Center on Aging, Health and Society, Northwestern Feinberg School of Medicine, Chicago, IL (2010–2012)
- Laurie Pane Foster, MEd (PC), Children's Hospitals and Clinics of Minnesota, University of Minnesota School of Public Health, Minneapolis, MN (2010-2015)
- Alison Kolste (PC), Children's Hospitals and Clinics of Minnesota (since 2015)

(B) Advisory Group
- Chris Feudtner, MD, PhD, MPH[a], The Children's Hospital of Philadelphia, Philadelphia, PA
- Sarah Friebert, MD, FAAP, FAAHPM[a], Akron Children's Hospital, Akron, OH
- Brian Greffe, MD[a], Denver Children's Hospital, Denver, CO
- Pamela S. Hinds, PhD, RN, FAAN[a], Children's National Health System, Washington, D.C.
- Stephen Liben, MD[a], McGill University and The Montreal Children's Hospital, Quebec, Canada
- S. Lawrence Librach, MD[a], Tammy Latner Centre for Palliative Care, Mt Sinai Hospital, Toronto, Canada
- Stacy F. Orloff, EdD, LCSW, ACHP-SW, Innovation and Community Health Empath Health, Clearwater, FL
- Christine Reilly, Parent Representative, Boston, MA
- Barbara Sourkes, PhD, Lucile Packard Children's Hospital Stanford, Palo Alto, CA
- Lauren Spiker, Parent Representative, Rochester, NY
- David Steinhorn, MD[a], UC Davis Children's Hospital, Sacramento, CA; Children's National Health System, Washington, D.C.

(C) Curriculum Writers Group
- Justin N. Baker, MD, FAAP, FAAHPM, St Jude Children's Research Hospital, Memphis, TN
- Donald Brunnquell, PhD, LP, Children's Hospitals and Clinics of Minnesota, Minneapolis, MN
- Brian Carter, MD, FAAP, Children's Mercy Hospital-Kansas City, Bioethics Center, Kansas City, MO
- Jody Chrastek, RN, DNP, CHPN, University of Minnesota Masonic Children's Hospital, Minneapolis, MN
- Rev. Kathleen Ennis-Durstine, M.Div., BCC, Children's National Health System, Washington, D.C.
- Maura Fitzgerald, RN, MS, MA, CNS Children's Hospitals and Clinics of Minnesota, Minneapolis, MN
- Richard Goldstein, MD, FAAP, Boston Children's Hospital, Dana-Farber Cancer Institute, Harvard Medical School, Boston, MA
- Julie Hauer, MD, Boston Children's Hospital and Seven Hills Pediatric Center, Boston, MA
- Ross M. Hays, MD, University of Washington School of Medicine and Seattle Children's Hospital, Seattle, WA
- Susan Huff, RN, MSN, Home Care and Hospice, John's Hopkin's Medical Center, Baltimore, MD
- Shana Jacobs, MD, Children's National Medical Center, Washington, D.C.
- Barbara Jones, PhD, MSW, The Institute for Grief, Loss, and Family Survival, UT Austin School of Social Work, Austin, TX
- Tammy Kang, MD, Children's Hospital of Philadelphia, Philadelphia, PA
- Jeffrey C. Klick, MD, Children's Healthcare of Atlanta, Emory University School of Medicine, Atlanta, GE
- Jennifer Mack, MD, MPH, Boston Children's Hospital, Dana-Faber Cancer Institute, Boston, MA
- Anna C. Muriel, MD, MPH, Dana-Farber Cancer Institute, Boston, MA
- Kaci Osenga, MD, FAAP, Cook Children's, Fort Worth, TX
- Kathy Perko, RN, MS, PNP, Bridges Palliative and Comfort Care Program, Doernbecher Children's Hospital at OHSU, Portland, OR
- Adam Rapoport, MD, FRCPC, MHSc, Hospital for Sick Children, University of Toronto, Toronto, Canada
- Helene Starke, PhD, MPH, Department of Bioethics and Humanities, University of Washington, Seattle, WA
- Tamara Vesel, MD, FAAHPM, Care Dimensions Hospice, Danvers, MA
- Lori Wiener, PhD, DCSW, Center for Cancer Research, National Cancer Institute, National Institutes of Health, Bethesda, MD

EPEC = Education in Palliative and End-of-Life Care; PI = principal investigator; CI = co-investigator; PC = program coordinator.
[a]Contributed as curriculum writers.

Appendix Table 2
EPEC-Pediatrics Conferences 2012–2019

Conference	Location	Date	In Collaboration/Conjunction With
1st "Become an EPEC-Pediatrics-Trainer" Conference	Boston, MA, U.S.	July 27, 2012	Beta-testing
2nd "Become an EPEC-Pediatrics-Trainer" Conference	Miami, FL, U.S.	April 27–28, 2013	ASPHO 26th Annual Meeting
3rd "Become an EPEC-Pediatrics-Trainer" Conference	San Diego, CA, U.S.	March 15–16, 2014	AAHPM & HPNA Annual Assembly
4th "Become an EPEC-Pediatrics-Trainer" Conference	Oak Brook, IL	Oct 16–17, 2014	(Adult) EPEC
5th "Become an EPEC-Pediatrics-Trainer" Conference	Toronto, ON, Canada	March 26–27, 2015	CPAC
6th "Become an EPEC-Pediatrics-Trainer" Conference	Montréal, Québec, Canada	April 31–May 1, 2015	CPAC
7th "Become an EPEC-Pediatrics-Trainer" Conference	Phoenix, AZ, U.S.	May 4–5, 2015	ASPHO 28th Annual Meeting
6th (and 1st in Spanish) LatinAmerican Train-the-Trainer Conference (Curso de Capacitatores EPEC-Pediatrico LatinoAmérica)	Montevideo, Uruguay	Sept 6–7, 2015	Uruguayan Society of Pediatrics; Teleton Fund
9th "Become an EPEC-Pediatrics-Trainer" Conference	Chicago, Il, U.S.	March 12–13, 2016	AAHPM & HPNA Annual Assembly
10th "Become an EPEC-Pediatrics-Trainer" Conference	Auckland, New Zealand	April 11–12, 2016	Starship Children's Hospital, Auckland, New Zealand
1st EPEC-Pediatrics Professional Development Workshop (PDW)	Montréal, QC, Canada	April 28, 2017	ASPHO 30th Annual Meeting
11th "Become an EPEC-Pediatrics-Trainer" Conference	Montréal, QC, Canada	April 29–30, 2017	ASPHO
12th "Become an EPEC-Pediatrics-Trainer" Conference	Nazareth, Israel	Nov 13–15, 2017	
EPEC-Pediatrics End-User Conference: Salzburg OSI Seminar in Pediatric Palliative Care.	Salzburg, Austria	Dec 3–9, 2017	Open Medical Institute/American-Austrian Foundation. Arenberg Castle
13th "Become an EPEC-Pediatrics-Trainer" Conference	Minneapolis, MN, U.S.	April 12–13, 2018	
2nd EPEC-Pediatrics Professional Development Workshop (PDW)	Minneapolis, MN, U.S.	April 14, 2018	
14th "Become an EPEC-Pediatrics-Trainer" Conference	Kuala Lumpur, Malaysia	May 18–19, 2018	Asia Pacific Hospice Palliative Care Network; Hospis Malaysia
15th "Become an EPEC-Pediatrics-Trainer" Conference	Memphis, TN, U.S.	Sept 24–25, 2018	St. Jude's Children's Research Hospital – For clinicians from low-medium income countries only
16th "Become an EPEC-Pediatrics-Trainer" Conference	Pune, India	January 19–20, 2019	Cipla Palliative Care & Training Centre
3rd EPEC-Pediatrics PDW	Sydney, Australia	March 6, 2019	PaPCANZ
17th "Become an EPEC-Pediatrics-Trainer" Conference	Sydney, Australia	March 8–9, 2019	PaPCANZ
18th "Become an EPEC-Pediatrics-Trainer" Conference[a]	Memphis, TN, U.S.	Sept 24–25, 2019	St. Jude's Children's Research Hospital – For clinicians from low-medium income countries only
19th "Become an EPEC-Pediatrics-Trainer" Conference[a]	*Minneapolis, MN, U.S.*	*Oct 2–4, 2019*	
4th EPEC-Pediatrics PDW[a]	*Minneapolis, MN, U.S.*	*Oct 5, 2019*	
20th (and 2nd in Spanish) LatinAmerican Train-the-Trainer Conference (Curso de Capacitatores EPEC-Pediatrico LatinoAmérica)[a]	*Buenos Aires, Argentina*	*Nov 1–4, 2019*	
EPEC Pediatrics Course	*Rome, Italy*	*Nov 20–23, 2019*	Maruzza Foundation

EPEC = Education in Palliative and End-of-Life Care; ASPHO = American Society of Pediatric Hematology/Oncology; AAHPM = American Academy of Hospice and Palliative Medicine; HPNA = Hospice and Palliative Nurses Association; CPAC = Canadian Partnership Against Cancer; PDW = Professional Development Workshop; PaPCANZ = Paediatric Palliative Care Australia and New Zealand; NIH/NCI = National Institutes of Health/National Cancer Institute.
Bold signifies conferences funded by NIH/NCI grant 2010–2017. Future conferences are italicized.
[a]In preparation at time of manuscript submission.

Appendix Table 3

Training Evaluation of Online Modules During NIH Grant Funding

Module Title (Responses $n =$)	I Have Obtained New Information (Knowledge) as a Result of Completing This Course	This Educational Activity Will Impact My Competency (Skills/ Abilities/Strategies Gained From the New Information).	This Educational Activity Will Impact My Performance (Implementing the New Skills/Abilities/ Strategies)	The Skills/Abilities/ Strategies I Have Obtained at This Activity Potentially Will Affect My Patient's Outcomes?
% Responding Yes				
M1. What is Pediatric Palliative Care (PPC) and Why Does it Matter: Palliative Care Overview (256)	75.78	80.39	77.25	78.57
M2. Child Development (166)	77.00	81.93	81.21	84.94
M3. Family-Centered Care (147)	66.67	74.66	76.03	78.47
M4. Grief and Bereavement (219)	85.84	87.61	85.78	87.96
M8. Ethical and Legal Considerations (133)	81.95	80.77	74.42	81.08
M10. Multi-Modal Analgesia (213)	89.20	91.00	88.63	92.49
M11. Opioid Selection and Rotation (178)	89.33	93.71	88.64	91.91
M12: Management of Neuropathic Pain Management and Adjuvant Analgesia (237)	96.20	94.87	90.21	93.22
M13: Procedural Pain Management Strategies (165)	85.37	84.24	80.98	86.50
Chronic/Complex Pain[a] (127)	91.20	92.80	88.71	92.13
M15. Gastrointestinal Symptoms (163)	89.57	88.27	83.85	88.68
M16. Respiratory Symptoms (244)	86.48	89.63	88.84	89.67
M17. Emotional and Behavioral Symptoms (184)	85.25	88.52	80.98	85.79
M18. Neurological Symptoms (147)	89.80	87.07	82.76	86.99
M19: Management of Refractory Distress (163)	88.34	89.51	83.95	88.57
M20: Preparation for Imminent Death (237)	78.81	89.45	88.56	89.18
M21: Integrative Medicine (149)	88.51	85.81	81.88	89.80
M22: Introducing Quality Improvement in PPC (197)	73.47	68.02	66.67	71.13
All 18 online modules	84.4	86	82.7	86.5

NIH = National Institutes of Health.

[a]Included M24: Methadone in the online version until 2018.