

Original Article

Education in Palliative and End-of-Life Care-Pediatrics: Curriculum Use and Dissemination



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Abstract

Context. The majority of seriously ill children do not have access to specialist pediatric palliative care (PPC) services nor to clinicians trained in primary PPC. The Education in Palliative and End-of-Life Care (EPEC)-Pediatrics curriculum and dissemination project was created in 2011 in response to this widespread education and training need. Since its implementation, EPEC-Pediatrics has evolved and has been disseminated worldwide.

Objectives. Assessment of past EPEC-Pediatrics participants' ("Trainers") self-reported PPC knowledge, attitudes, and skills; use of the curriculum in teaching; and feedback about the program's utility and future direction.

Methods. From 2011 to 2019 survey of EPEC-Pediatrics past conference participants, using descriptive and content analyses.

Results. About 172 of 786 (22% response rate) EPEC-Pediatrics past participants from 59 countries across six continents completed the survey. Trainers, including Master Facilitators (MFs), used the curriculum mostly to teach interdisciplinary clinicians and reported improvement in teaching ability as well as in attitude, knowledge, and skills (AKS) in two core domains of PPC: communication and pain and symptom management. The most frequently taught modules were about multimodal management of distressing symptoms. Trainers suggested adding new content to the current curriculum and further expansion in low-medium income countries. Most (71%) reported improvements in the clinical care of children with serious illnesses at their own institutions.

Conclusion. EPEC-Pediatrics is a successful curriculum and dissemination project that improves participants' self-reported teaching skills and AKS's in many PPC core domains. Participating clinicians not only taught and disseminated the curriculum content, they also reported improvement in the clinical care of children with serious illness. *J Pain Symptom Manage* 2022;63:349–358. © 2021 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Pediatric, palliative care, education, survey, curriculum, training

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EDITORIAL COMMENT*Amy Case MD, FAAHPM Associate Editor*

Excellent submission describing EPEC-PEDS which is important for others to learn more about.

Key Message

This article describes findings from a global survey of clinicians who received EPEC-Pediatrics training over a nine-year period, including the impact the course had on their knowledge, attitudes, skills, and teaching of others. The course had a positive impact internationally, and importantly, was perceived as improving care of children with serious illness.

Introduction

Education in pediatric palliative care (PPC) is in high demand worldwide¹ with lack of clinician training cited as a major barrier to accessing skilled palliative care services for patients and their families.² Professional education and development in palliative care has been encouraged by the Institute of Medicine report *Dying in America: Improving quality and honoring individual preferences near the end of life*, and by numerous other pediatric organizations,^{3–5} and researchers.^{6–13}

In response to the need for more widespread palliative care training for all pediatric clinicians to enable delivery of primary PPC, and the dearth of advanced training in the prevention and treatment of pain and other distressing symptoms, the Education in Palliative and End-of-Life Care (EPEC)-Pediatrics program was conceptualized and funded through a US\$1.6 million National Institutes of Health and/or National Cancer Institute (NIH/NCI) R25 grant.¹⁴

The curriculum is delivered through a combination of online learning and in-person, face-to-face sessions and comprises 24 core palliative care modules, with 18 modules available online and 6 taught in-person by “Master Facilitators” (MF) at “Train-the-Trainer” (TtT) conference sessions. The EPEC-Pediatrics training approach places strong emphasis on teaching participants advanced teaching skills such as how to disseminate PPC concepts to others in engaging ways that foster acquisition of attitudes, knowledge, and skills (AKS), that in turn achieve desired clinical outcomes.¹⁵ These TtT courses provide “Trainers” (pediatric clinicians) with 22 adaptable PowerPoint presentations, all training videos, and a Trainer’s handbook for each module to teach interdisciplinary teams. Trainers can adapt these materials as necessary for teaching interprofessional colleagues across a variety of settings. Trainers who are interested in becoming a MF must attend an EPEC-Pediatrics Professional Development Workshop (PDW) that emphasizes professional teaching techniques including interactive lecture, and small group and/or case-based teaching role-play using the curriculum.¹⁴

While several PPC curricula are available through academic and non-profit organizations in the US and internationally,^{15–23} EPEC-Pediatrics remains the largest and most comprehensive PPC training curriculum and dissemination projects worldwide, and has been translated from English to Spanish, Russian and French. The curriculum is constantly being updated, adapted, and expanded to encourage interdisciplinary, global participation. In this study we surveyed past EPEC-Pediatrics participants to examine how they have used EPEC-Pediatrics course materials to teach PPC in their own communities, and whether EPEC-Pediatrics had an impact on their own PPC AKSs.

Methods*Participants*

We invited all past EPEC-Pediatrics participants who completed at least the face-to-face conference component of the EPEC-Pediatrics TtT or PDW courses (i.e., Trainers and MFs) between October 2011 and early 2019, regardless of whether or not they completed the online training portion (80% completed the 18 online modules).

Survey Instrument

The survey contained forced-entry and open-ended items including personal and professional characteristics (e.g., race, profession, country of residence); geographical dissemination of EPEC-Pediatrics (US states, Canadian provinces, Australian territories, and countries); dissemination of EPEC-Pediatrics through teaching (e.g., which modules have been taught and to whom); perceived improvement in AKSs as a result of attending EPEC-Pediatrics (pain and symptom management; teaching PPC; communicating with colleagues about PPC); improvement in the clinical care setting as a result of attending EPEC-Pediatrics (e.g., institutional improvement in care of children with serious illness); and general feedback about the program, including suggestions for program improvement and ways in which the program can be adapted for implementation in low- and medium-income countries.

Procedures

The survey was granted exemption by the Children’s Hospitals and Clinics of Minnesota’s Institutional Review Board. REDCap software²⁴ was used to implement the survey. A unique survey link was emailed to eligible participants in early summer of 2019. Two reminders were sent to non-responders during a four-

week period. Participants who completed the survey received a US\$10 gift card for their participation.

Statistical Analysis

Descriptive statistical analyses were conducted using IBM SPSS v27. Means, standard deviations (SD), medians and interquartile ranges (IQR) were run for continuous variables; and frequencies and percentages were run for categorical variables. Manual sorting and content analysis to identify frequency of common categories was conducted for each of the open-ended items using Microsoft Excel.^{25,26}

Table 1

Survey Respondent Characteristics (n = 172)

Characteristic	n (%)
Female gender, n = 170	138 (81)
Race, n = 165	
White	102 (62)
Asian	45 (27)
Other ^a	11 (7)
Black	3 (2)
Ethnicity, n = 164	
Hispanic or Latino	23 (14)
Years of post-graduate work experience, mean (SD) n = 152	14.2 (9.9)
Palliative care fellowship training	
Formal pediatric fellowship, hospice and palliative medicine	21 (12)
Formal adult fellowship, hospice and palliative medicine (with pediatric track)	14 (8)
Formal adult fellowship, hospice and palliative medicine (without pediatric track)	7 (4)
Country in which most respondents work ^b , n = 170	
United States	46 (27)
Canada	38 (22)
Australia	10 (6)
Israel and Occupied Territories	7 (4)
Malaysia	6 (4)
New Zealand	6 (4)
Singapore	6 (4)
Others (xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx)	33 (19)
Has experience working in low-/ middle-income countries, n = 157	
Yes	65 (41)
EPEC-Pediatrics Trainer level, n = 170	
EPEC-Pediatrics Trainer (online curriculum plus face-to-face conference)	110 (65)
TtT conference attendee only (has not completed online curriculum)	33 (19)
Master Facilitator and/or part of original Expert Advisory Group	26 (15)
Other ^c	1 (<1)
Conference attendance, top locations and year (n = 172) ^d	
Kuala Lumpur, Malaysia (2019)	21 (12)
Sydney, Australia (2019)	18 (11)
Chicago, Illinois, USA [in conjunction with AAHPM and HPNA Annual Assembly] (2016)	18 (11)
Montreal, Quebec, Canada in conjunction with ASPHO 30th Annual Meeting (2017)	17 (10)
Montreal, Quebec, Canada (2015)	16 (9)
St. Jude Children's Research Hospital, Memphis, Tennessee, USA (2018)	12 (7)
Toronto, Ontario, Canada (2015)	12 (7)

(Continued)

Results

Participant Characteristics

Between October 2011 and March 2019, a total of 786 participants from 61 different countries attended a TtT conference or TtT conference plus PDW. A total of 172 (22% response rate) EPEC-Pediatrics past participants completed the survey. The majority of respondents were female (81%), with an average of 14.2 (SD = 9.9) years of post-graduate work experience and 40 (23%) had completed a formal palliative care fellowship for at least one year post-residency. Survey respondents included at least one participant from each of the offered conferences, with the highest

Table 1 Continued

Characteristic	n (%)
Montevideo, Uruguay (2015)	11 (6)
Auckland, New Zealand (2016)	11 (6)
Minneapolis, Minnesota, USA (2018)	10 (6)
Oak Brook, Illinois, USA (2014)	10 (6)
Profession, n = 172	
Physician	110 (64)
Nurse	31 (18)
Nurse Practitioner	20 (12)
Educator	3 (2)
Psychologist	2 (1)
Social Worker	2 (10)
Administrator	1 (<1)
Has provided PPC in the last 2 years, n = 171	151 (88)
Works as part of a designated PPC team, n = 151	
Yes	98 (65)
Full-time	52 (55)
Part-time	43 (45)
No, work as part of another team (e.g., oncology)	53 (35)
Provides primary palliative care as part of the following programs, n = 75	
Pediatric Oncology	36 (21)
Pediatric Hematology	11 (6)
General Pediatrics	9 (5)
Pediatric Pain Medicine	4 (2)
Adult Medicine	3 (2)
Pediatric Intensivist	2 (1)
Neonatology	2 (1)
Family Medicine	1 (<1)
Pediatric Hospitalist	1 (<1)
Other ^e	6 (3)

AAHPM = American Academy of Hospice and Palliative Medicine, HPNA = Hospice and Palliative Nurses Association, ASPHO = American Society of Pediatric Hematology/Oncology.

^a“Other” race descriptions included mestizo/a; ethnicity as race (Hispanic or Latina/o); or countries of origin (Africa, Arabia, Peru, Spain).

^bSee Figure 1 for map of all countries.

^cThe respondent who selected “Other” did not provide an explanation.

^dSurvey participants could select more than one conference, and some participants also completed a Professional Development Workshop following the main conference. Conferences that were also attended by survey participants included Boston, Massachusetts beta conference, USA, 2012 (n = 9); Phoenix, Arizona, USA, 2015 (n = 9); Coimbatore, India, 2017 (n = 8); Nazareth, Israel, 2017 (n = 7); Pune, India, 2016 (n = 4); San Diego, California, USA in conjunction with AAHPM/HPNA Annual Assembly, 2014 (n = 4); Miami, Florida, USA in conjunction with ASPHO 26th Annual Meeting, 2013 (n = 4); and Pune, India, 2019 (n = 2).

^e“Other” includes hospice work, neurology with focus on neuromuscular disease (n = 2), pediatric home care work, pediatric nephrology, adult palliative care service that occasionally receives pediatric cases.

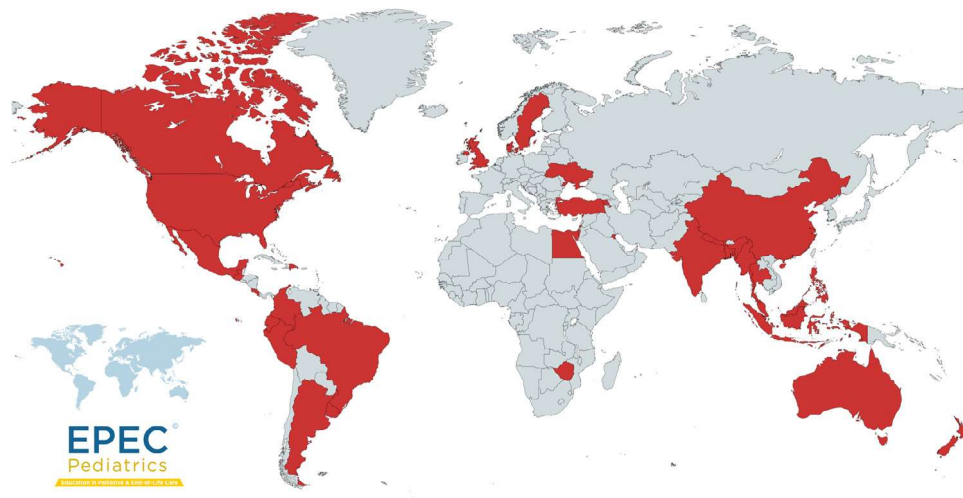


Fig. 1. Countries represented by survey respondents.

representation from the following five conference locations: Kuala Lumpur, Malaysia 2018 ($n=21$); Sydney, Australia 2019 ($n=18$); Chicago, IL, USA 2016 ($n=18$); Montreal, Canada 2017 ($n=17$); Montreal, Canada 2015 ($n=16$) (Table 1 for a complete listing). Most survey respondents participated in at least one TtT conference between 2015 and early 2019 and only 19 (11%) participated in a conference prior to 2015. Respondent characteristics are shown in Table 1.

Geographic Dissemination

Survey respondents were from 34 of the 61 different countries represented by EPEC-Pediatrics participants (Fig. 1). The majority of teaching took place in the countries where respondents worked including: United States ($n=41$); Canada ($n=37$); Australia ($n=10$); India ($n=10$); Malaysia ($n=7$); Uruguay ($n=7$); and Singapore ($n=6$) which was similar in distribution to

people's primary work locations shown in Table 1. Of the 41 respondents from 29 US states or territories, the majority had taught using EPEC-Pediatrics in the following states: Tennessee ($n=9$); California ($n=7$); Massachusetts ($n=7$); Florida ($n=5$); and Texas ($n=5$), while no survey respondents had taught in 24 states and five Territories. The Canadian survey respondents had taught in all provinces except Prince Edward Island, Saskatchewan, and the Yukon Territory.

Teaching Experience with EPEC-Pediatrics

One hundred and fifty-three (89%) respondents accessed at least one type of EPEC-Pediatrics teaching modality (i.e., PowerPoint slides, teaching guides, trigger videos). One hundred and thirty-four (79%) survey participants taught PPC since attending an EPEC-Pediatrics training event, and 97 of 134 (72%) have used EPEC-Pediatrics materials to teach. Fig. 2 shows the

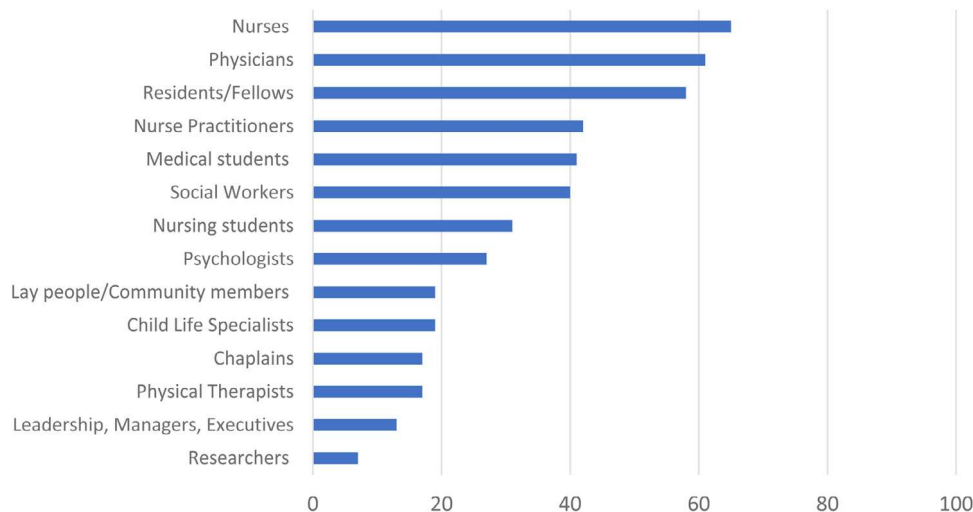


Fig. 2. Proportion of survey respondents who reported teaching EPEC-Pediatrics contents by role or discipline of the recipient ($n=172$).

variety of roles and disciplines held by those trained by the survey respondents. Most reported teaching to nurses (65%) and physicians (61%).

Most Useful Modules and Teaching Methods

Ninety-seven respondents used at least one of the EPEC-Pediatrics modules to teach PPC (Table 2). The most frequently taught module was *What Is Palliative Care?* (76%) which was taught a median of five times (IQR=7). The next four most-taught modules were focused on symptom management (acute pain, opioid selection, neuropathic pain, and respiratory symptoms). Content analysis of open-ended responses indicated the most useful aspects of the EPEC-Pediatrics curriculum were learning new teaching skills ($n=29$), learning about pain and symptom management ($n=21$), gaining new communication skills ($n=19$), and the teaching materials themselves (breadth, depth, access to, and quality [$n=14$]). Content analysis of 86 responses to other ways EPEC-Pediatrics has changed how they provide PPC indicated their teaching skills had improved ($n=25$) and their confidence or excitement about teaching others has improved since

becoming a Trainer ($n=8$). Some respondents said they have successfully taught specific types of professionals (e.g., residents, fellows) ($n=6$) and some felt becoming an EPEC-Pediatrics Trainer elevated their status as a PPC educator within their institution ($n=4$).

Impact of EPEC-Pediatrics on Participants' Knowledge, Attitudes, and Skills

Pain and symptom management: The majority of respondents agreed or strongly agreed that EPEC-Pediatrics improved their knowledge (86%), attitudes (77%) and skills (91%) in pain and symptom management. Content analysis of other ways in which EPEC-Pediatrics impacted their approach to pain and symptom management revealed that nearly one quarter of the 89 respondents shifted their approach to one that is more holistic and incorporates non-pharmacologic approaches ($n=20$). Others said they are now aware of the importance of systematic assessment and re-assessment of symptoms ($n=7$), gained confidence in their knowledge of symptom management ($n=7$), and their approach to teaching symptom management had improved ($n=7$). Others have become overall

Table 2

Most Frequently Accessed Modules by Past Participants Who Have Taught Using EPEC-Pediatrics Teaching Materials ($n=97$)

Module Number	Module Title	Number of Respondents Who Have Used Module to Teach PPC	Number of Times Each Respondent has Used Module to Teach, Median (IQR)
1	What is Pediatric Palliative Care?	74	5 (7)
10	Multimodal Analgesia: Acute pain Management	61	4 (5.25)
12	Neuropathic Pain Management and Adjuvant Analgesia	59	3 (3.5)
11	Opioid Selection and Opioid Rotation	53	4 (5.5)
16	Management of Respiratory Symptoms	52	3 (4)
20	Preparation for Imminent Death	51	4 (6.25)
7	Communication and Planning	46	4 (3.75)
14	Chronic/Complex Pain Management	41	3 (4)
15	Management of Gastrointestinal Symptoms	40	3 (5.5)
18	Management of Neurological Symptoms	38	2.5 (4.75)
4	Grief and Bereavement	37	3 (4)
17	Management of Emotional and Behavioral Symptoms	34	2.5 (4)
19	Management of Refractory Distress	34	3 (5.5)
5	Self-Care for Professionals	33	3 (5.25)
23	Teaching Pain and Symptom Management	32	3 (4)
13	Procedural Pain Management Strategies	31	3 (3)
3	Family-Centered Care	30	3 (3)
8	Ethical and Legal Considerations	30	2 (3)
6	Team Collaboration and Effectiveness	27	2.5 (3)
21	Integrative Medicine	26	3 (5.5)
2	Child Development	23	2.5 (2)
24	Methadone	21	1 (2)
9	Teaching with EPEC-Pediatrics in the Face-to-Face Setting	12	2.5 (3.5)
22	Introducing Quality Improvement in Pediatric Palliative Care	11	2 (2)

Table 3
Examples of Written Open-Ended Survey Responses

Question	Responses	
Has EPEC-Pediatrics impacted the way you approach pain and symptom management in other ways?	I am now more aware of the impact of integrative therapies and have included training on these in my course.	<i>It has reinforced, and actually led to, practice change in using multimodal pain management and reinforced the need to listen to the child as a judge of their symptoms.</i>
Has EPEC-Pediatrics impacted your ability to communicate with others about PPC in other ways?	<i>Yes, since I am confident about handling certain aspects of care and communication especially related to de-escalation of therapy and end-of-life care.</i>	<i>EPEC has allowed me more confidence in discussing topics with families but more importantly my abilities and confidence in discussions with other staff</i>
Anything additional you wish to share with us about how EPEC Pediatrics has impacted your ability to teach, the way you approach teaching, and your abilities to communicate with others about PPC?	<i>I have learned how to structure my sharing in a way that would be more powerful than just plainly explaining knowledge and skills alone.</i>	<i>EPEC Pediatric content is integrated into our Pediatric Palliative Care workshops that we offer annually.</i>
Please describe which aspects of EPEC-Pediatrics you have found to be most useful	<i>An organized, well written complete curriculum. 'One stop shopping'. It provides good information and examples of how to teach the information</i>	<i>Content is best pediatric palliative care training for practitioners with all levels of experience as material is self-taught and focus of class is on how to teach which is fantastic skill many practitioners don't get during their training</i>
If not already mentioned above, describe how EPEC-Pediatrics has changed the ways in which you provide PPC	<i>Despite limit in the choice of morphine formulation, we have made children pain free. I have also extended service beyond cancer and now included children of life-threatening diagnoses.</i>	<i>At my institution we are now more aware of PPC, not only from a physician's point of view. I have also been able to influence the region so cooperation with home care providers has increased, though this can still be improved more.</i>
What is working well with EPEC-Pediatrics, and what should we maintain?	<i>It is comprehensive, which should be continued. The access to slides and resources is good.</i>	<i>I find the arrangement of the topics to have a good flow, particularly when working with 'early' learners (medical students/residents).</i>
Where do you see room for improvement?	<i>Provide more information about available medications in different parts of the world, so the pharmacological management could be more relevant to each local setting.</i>	<i>Accompanying documents that could be used easily for a quick teaching session (such as a 1-pager on nausea pathways and medications). In pdf format for sharing with residents/learners. Another option would be an opioid conversion tool as one page</i>
We are developing an EPEC-Pediatrics for low- and medium-income countries. What content would need to be changed, added, or which modules might be missing?	<i>Cultural humility and sensitivities. PPC for the severely neurologically disabled. Some medications and integrative services are not easily available.</i>	<i>The pediatric oncology teams are limited to a few busy physicians and a very small number of nurses in most of these countries. They need practical solutions for limited resources, and emotional support for their high level of anxiety and frustration originating from the feeling of incapacity</i>

advocates for change within their departments or institutions ($n=5$) and some described the value of learning differences in symptom management in adults versus children ($n=5$). Respondents also indicated that EPEC-Pediatrics has provided them with medication-specific knowledge ($n=8$) (e.g., morphine, gabapentin, methadone, managing multiple distressing symptoms, and when to undertake opioid rotation). See Table 3 for examples of open-ended survey responses

Teaching PPC: The majority of past participants agreed or strongly agreed that their knowledge (86%), attitudes (77%) and skills (91%) in teaching PPC to others had improved.

Others have increased their use of patient care-focused methods (e.g., bedside teaching, telemedicine). About 94 of 171 (55%) agreed or strongly agreed that participation in EPEC-Pediatrics has resulted in more teaching opportunities at their institutions. When asked what *other* teaching approaches they have used respondents described using 1:1 teaching ($n=4$)

or interactive methods requiring direct participation ($n=7$). Examples include reflection journaling; simulation sessions; starting sessions with a “chalk talk” list of topics participants wish to learn; asking each audience member to share their most difficult case; asking participants to breathe through straws for a lesson on dyspnea; using techniques such as Attract Attention, Inform, Create Desire, Act (AIDA), or “think, pair, share”; and sharing challenging clinical situations and asking participants to join groups of colleagues around the room whose proposed solution aligns with theirs.

Communicating about PPC: The majority of participants reported overall improvements in knowledge (84%), attitudes (81%), and skills (82%) in communication with others. Most also reported improvement (i.e., agree and/or strongly agree) in who they communicate with about PPC across four different communication domains: communication with others (82%), communication with colleagues and/or other clinicians (86%), communication with patients and/or families (82%), and communication with leadership and/

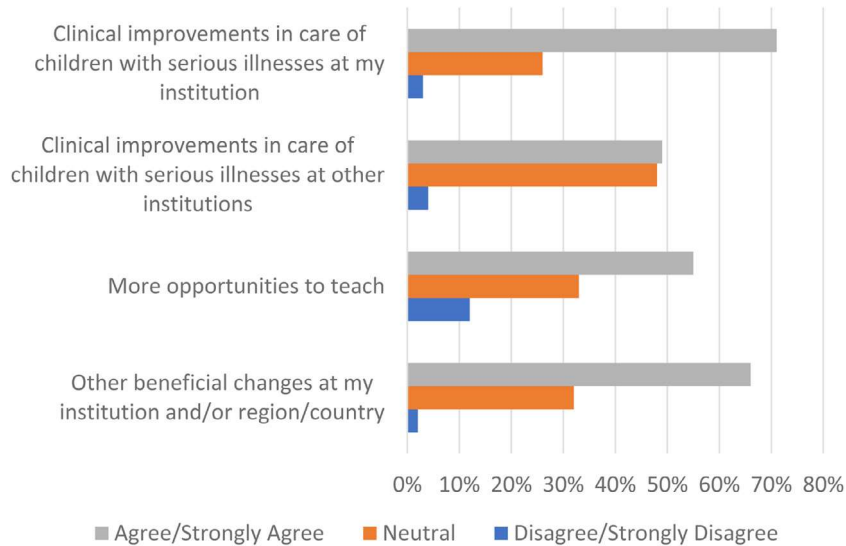


Fig. 3. Outcomes experienced as a result of participating in EPEC-Pediatrics.

or administration (75%). Content analysis of *additional* ways in which EPEC-Pediatrics has impacted their ability to communicate with others about PPC showed a similar pattern with the ratings above (i.e., their skills and confidence improved in communicating with colleagues ($n=12$), patients and families ($n=8$), and leadership ($n=5$)). Some described seeing themselves as better advocates for PPC ($n=5$) (e.g., early integration of PPC). Others described how specific communication skills have improved their clinical care, such as breaking bad news to families and guiding colleagues in pain management approaches ($n=9$).

Content analysis of the question asking respondents to share *anything else* about how EPEC-Pediatrics has impacted their ability to teach or communicate with others about PPC revealed that participants felt their overall teaching skills have improved ($n=24$) (e.g., less reliance on slides, providing more learner participation opportunities such as case-based role play, story-telling, audience knowledge). Some described how EPEC-Pediatrics inspired them to advocate for local PPC training ($n=13$) (e.g., creating annual workshops, designing formal courses, rural outreach teaching programs, giving input into Oncology - PPC program integration). Others appreciated the adaptability of the teaching materials to different audiences and situations ($n=9$) (e.g., slides can be modified on short notice, teaching videos are easy to incorporate).

Benefits of EPEC-Pediatrics Participation

One hundred and twenty (71.0%) respondents agreed or strongly agreed that they have seen clinical improvements in the care of children with serious illnesses at their own institutions as a result of participation in EPEC-Pediatrics, while 44 (26%) were neutral and only five (2.9%) disagreed. Eighty-three (49%)

agreed or strongly agreed that they have seen clinical improvements in the care of children with serious illnesses at *other* institutions as a result of EPEC-Pediatrics, while 112 of 170 (66%) have seen other beneficial changes at their institution or at the regional and/or national level. See Fig. 3 for more detail.

Program Strengths, Weaknesses, and Suggestions for Adaptations in Lower-Resource Settings

Content analysis of the question asking participants to describe what was working well and should be maintained showed that some participants liked the curriculum itself because of its breadth, quality, length, and organization ($n=23$), with some participants appreciating the online modules ($n=6$) and others describing the value of the symptom-focused modules ($n=4$). Some participants said all aspects of the EPEC-Pediatrics program are working well ($n=22$) and that they should be maintained while some described the quality and accessibility of the teaching materials ($n=15$) and the adaptability of the PowerPoint slide decks. The EPEC-Pediatrics teaching approach was described as valuable ($n=10$).

When asked how EPEC-Pediatrics could be improved, 107 respondents suggested new module topics ($n=18$), such as management of delirium, the role of cannabis, the role of philanthropy in PPC, caring for special populations (e.g., neonates, cardiology), how to start a new service, research and outcome measures, physician-assisted suicide, and additional cultural adaptations ($n=9$) including incorporation of differences in analgesic availability by country ($n=4$).

Others said materials should be updated and modified over time (including editorial updates) ($n=7$), and that the updated materials should be re-issued to past participants so that they have access to the latest

evidence. Some specifically addressed the need to update the trigger tape video content for use outside the US ($n=8$). A few respondents felt the teaching materials or modules were too lengthy ($n=5$) while others felt more didactic sessions and conferences should be offered ($n=7$). When asked how content should be modified in order to expand EPEC-Pediatrics offerings to people living in low- to medium-income countries, 13 of the 51 respondents suggested addressing lack of analgesic availability and access by country; modifying or adding modules emphasizing the importance of cultural humility and sensitivity in PPC ($n=10$); discussing alternative care options in limited-resource settings ($n=6$) (e.g., limited staffing, rural settings); emphasizing the importance of honoring religious and spiritual beliefs in PPC ($n=4$) (e.g., fear of abandonment, alternative treatments); and discussing how to build and sustain PPC programs in limited-resource settings ($n=6$).

Discussion

EPEC-Pediatrics represents the most comprehensive PPC curriculum and dissemination project worldwide.^{14,27} As a program designed to train clinicians of all disciplines in the core competencies of pediatric palliative care, it responds to the recognized need to increase the number of clinics with “primary palliative care knowledge” and skills.²⁸ Findings from this survey of a cohort of past EPEC-Pediatrics participants suggest that EPEC-Pediatrics improved participants’ self-reported knowledge, skills, and attitudes across core PPC domains, including advanced pain and symptom management, teaching PPC, and communication. Participating clinicians from six continents not only taught and disseminated the curriculum content, but also reported perceived improvement in the clinical care of children with serious illness in their institutions and regions.

The most commonly used module for teaching was *What is Pediatric Palliative Care?*, similar to Widger et al.’s (2018) findings during their large-scale, enhanced EPEC-Pediatrics project implemented across all Canadian provinces.²⁷ Not only was it the most used module amongst all Trainers, but it was used a median of five times by Trainers. This was the only module in the top five most-taught that was unrelated to symptom management and analgesia. This could be due to a relatively seasoned group of interprofessional PPC clinicians recognizing the widespread need for teaching core PPC concepts to a variety of colleagues and learners in their institutions and communities who may not be familiar with fundamentals of PPC. Teaching about symptom relief and analgesia was a high priority for this sample, suggesting they recognize clinicians’ low confidence in providing symptom management for children with

serious illness that has previously been described in the literature.^{29–31} Responses indicated most respondents felt they gained new AKSs, with many describing their new approach to symptom assessment and management as more holistic (e.g., incorporating integrative “non-pharmacologic” management) and utilizing a systematic step-wise treatment approach. Requests for EPEC-Pediatrics materials to acknowledge inter-country differences in analgesic medication nomenclature and availability have been noted.

Most past EPEC-Pediatrics participants have accessed the teaching materials, and a large percentage of them have taught PPC using them, with nurses as the most common trainees. While nursing education in PPC has improved in the last decade,¹⁶ there remains much work to be done across a variety of healthcare settings.³² Many of the survey respondents had also leveraged EPEC-Pediatrics materials to teach post-graduate physicians and trainees such as residents and/or fellows or medical students, indicating EPEC-Pediatrics has positively impacted the void in didactic and hands-on PPC training typically available to early career physicians.^{6–9,29,33} One of the core EPEC-Pediatrics training topics is communication. Open-ended survey responses indicated that Trainers’ new EPEC-Pediatrics communication skills were highly valued. This is important because research has shown that children with serious illness and their families rate clear and open communication as very important when facing end-of-life (EOL) planning and decision-making^{34–36} and that poor communication can have a detrimental effect on a family’s EOL experience.^{37,38} However, training clinicians in communication about EOL in the PPC context has historically lagged in part due to low numbers of PPC patients seen during early clinical training rotations.^{13,33,39} During TtT conferences, communication skills are taught using different approaches (e.g., role play, trigger tape videos), suggesting hands-on participation and an expanded toolbox likely led EPEC-Pediatrics Trainers to feel more confident in teaching these challenging yet vital PPC topics, with 46% of participants going on to teach *Communication and Planning* and 51% teaching *Preparation for Imminent Death*.

EPEC-Pediatrics is one of several PPC training programs worldwide^{13,15–23,40–43} but it is unique in several ways. First, teaching clinicians *how to teach* PPC effectively is a hallmark of the program. Open-ended survey responses revealed that participants placed high value on the new teaching skills they acquired. Second, it is a comprehensive PPC curriculum offering fundamental and advanced topics and tools that can be tailored and taught to any audience or situation. Third, its global reach as a dissemination project is expansive and participation is encouraged through scholarship opportunities and language translations. Experienced EPEC-Pediatrics Master Facilitators are located around the

world on all populated continents and encouraged to collaborate and host their own programs. EPEC-Pediatrics targets participants who are non-fellowship trained, practicing clinicians with some experience with PPC rather than novice students or clinicians representing a single discipline (e.g., nurses).^{21,39} While some PPC training programs have been offered a limited number of times^{40,43} or in a single format,⁴² EPEC-Pediatrics is one of the most flexible, comprehensive, long-running PPC training programs available with 1,517 clinicians from 100 countries trained to date.

Limitations

The extent to which the opinions of those who chose to participate are representative of all past EPEC-Pediatrics participants is unknown due to the relatively low response rate. However, there was at least one respondent from each of the past conferences and the response rate was within the expected range.⁴⁴ The majority of respondents were physicians, and while this is reflective of actual EPEC-Pediatrics participation, opinions may not be shared by all PPC disciplines. This survey is a helpful step toward assessing the impact and dissemination of EPEC-Pediatrics, but responses should be interpreted with caution as they are self-reported perceptions rather than measurable indicators of EPEC-Pediatrics' impact on clinical outcomes and AKSs. Pre-post conference AKS assessments were conducted during the initial NIH and/or NCI grant funding period, but the focus of this survey was longer-term use of the materials and dissemination. Going forward, there may be benefit to conducting an annual survey. Past participants from earlier conferences were not as well represented, but this was not surprising considering several years have passed, contact information may have changed, and the full complement of modules was not available until 2015. Conversely, some participants may not have had adequate time for implementation. Despite over 70% of survey respondents indicating their training led to improvements in the care of children with serious illness, it was unclear from the data why nearly one-quarter were neutral, warranting further exploration.

Next Steps

The COVID-19 pandemic presented logistical challenges for the EPEC-Pediatrics program, but its flexibility and adaptability to a virtual platform were demonstrated through a successful global TtT conference and two end-user conferences between March and October 2021. The use of a virtual platform, reduced participation fees, and global EPEC-Pediatrics leadership collaboration encouraged widespread participation across time zones and languages (English and Spanish). The EPEC-Pediatrics curriculum will continue to evolve in response to new training needs and priorities, such as the need to expand training to all clinicians who care for children with all types of

serious illness; the expressed desire to expand the psychosocial aspects of the program; to encourage greater participation from the full range of professions that are integral to the successful delivery of family-centered PPC; and the need to expand global outreach and participant accessibility through culturally-sensitive means including translation to more languages.

Summary/Conclusion

Survey findings of past EPEC-Pediatrics participants were positive and showed that EPEC-Pediatrics improves participants' attitudes, knowledge and skills across core PPC domains. Participants created teaching opportunities in their own institutions and communities, and many felt that their efforts translated into notable improvements in the care of children with serious illness at their own institutions and beyond.

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