

**EDUCATION AND TRAINING RESOURCES
FOR PEDIATRIC PALLIATIVE AND HOSPICE
CARE PROVIDERS AND PROGRAMS**

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Pediatric e-Journal

Pediatric Palliative and Hospice Care

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Issue Topic: Education and Training Resources for Pediatric Palliative and Hospice Care Providers and Programs

Welcome to the 71st issue of our Pediatric e-Journal. In this issue, we focus on education and training resources for providers and programs that are already involved in the delivery of pediatric palliative and hospice care. In Issue #72, we will concentrate on education and training resources for providers and programs that are currently working in the delivery of adult palliative and hospice care, but who may find themselves called upon to care for a child or adolescent and those young people's family members.

Our goal in this issue is to bring together as wide a range of education and training resources for providers and their programs as we can draw together in a single issue. Once upon a time, there would have been few education and training resources of this type. Now there are many and we decided it might be useful to gather together as many of them in one convenient source.

We do not expect that a single issue of our e-Journal will cover every possible education and training resource in pediatric palliative/hospice care, but we hope to guide readers to as many of them as possible, with emphasis on those that are most prominent and most useful—and perhaps to draw attention to some that may be less widely known.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. Chuck Corr is our Senior Editor. Archived issues of this publication are available at <https://www.nhpco.org/palliativecare/pediatrics/>

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics for future issues in 2023 like education and training resources for adult hospice programs that are asked to care for a child, and multidisciplinary approaches to pediatric symptom management. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at christytork@gmail.com or Suzanne Toce at tocess@gmail.com.

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

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Chrissy Salley, Ph.D

"Courageous Parents Network (CPN) is a national nonprofit, 501(c)(3) organization that provides curated digital resources and programming to help parent caregivers advocate for their children living with serious illness and navigate the illness journey. Its mission is to orient and empower caregivers and others by providing them with resources and tools that reflect the experience and perspective of other families and clinicians." This article describes CPN's clinician portal, its caregiver's resources as educational tools, live virtual events, and speaking engagements.

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Suzanne S. Toce, MD FAAP

"CAPC is one of the oldest multidisciplinary sources of palliative care educational material... CAPC was formed in 1999, to improve the lives of people living with serious chronic medical conditions and those caring for them." This article describes examples of the "the 'toolkits' focused on pediatric palliative care (PPC) on the CAPC website [that] are very helpful in outlining aspects of setting up a PPC program and training the providers." The examples include PPC billing and business planning; PPC delivery toolkit; and online courses.

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This article is a report on the End-of-Life Nursing Education Consortium (ELNEC) project, "a national education initiative to improve end-of-life care and continues to be the gold standard in palliative care education. The project uses a train-the-trainer approach to provide nurses and other interprofessional team members with education in palliative and end-of-life care on topics including pain and symptom management, communication, ethics, care at the time of death, loss, grief, and bereavement, and self-care." Included in this report are descriptions of the growth of ELNEC pediatric (including perinatal and international initiatives) and future work.

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Andrea Postier, PhD, MPH, Stefan J. Friedrichsdorf, MD, FAAP, Ximena Garcia-Quintero, MD, MS, Justin N. Baker, MD, FAAP, FAAHPM, and Stacy Remke, MSW, LICSW, APHSW-C, FNAP

"The Education in Palliative and End of Life Care-Pediatrics (EPEC-Pediatrics) program was developed to fill a void in pediatric palliative care (PPC) training and dissemination." Since its inception, "EPEC-Pediatrics has evolved and expanded in many ways with global accessibility at its core. To date, we have trained 1,774 clinicians from 114 countries across 6 continents who are EPEC-Pediatrics Trainers (1,104), Master Facilitators (MF, 125), and end-users." This article describes: the curriculum content and 3 levels of EPEC-Pediatrics training; the EPEC-Pediatrics approach to teaching; and EPEC-Pediatrics during the COVID-19 pandemic. Also included is an extensive table outlining EPPEC-Pediatrics modules and objectives.

The Network of Pediatric Palliative Care Educators

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Katharine Brock, MD, MS, FAAHPM, Naomi Goloff, MD, FRCPC, FAAHPM, and Amy Trowbridge, MD

This article is a report on "The Network of Pediatric Palliative Care Educators (NPPCE) launched in January 2022 with the goal of advancing access to quality interprofessional pediatric palliative care education through a community for collaboration and dissemination of educational best practices, research, and resources. The vision of NPPCE is to transform palliative care education through organization of an interprofessional community of educators, with the ultimate goal of improving care for children with serious illness and their families...NPPCE launched in January 2022, and so far has nearly 400 registered members! We completed one full year of programming and hosted an in-person gathering at the recently Annual Assembly in Montreal on March 23, 2023. NPPCE is open internationally to all types of interprofessional team members who teach pediatric palliative care... The plan is to continue to hold every-other-month educational sessions and promote collaboration around educational projects."

Experiences in Pediatric Palliative Care Interdisciplinary Education

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Patrick Lloyd, DO, MA

In this article, the author makes a strong argument for the value of interdisciplinary vs. multidisciplinary teamwork in pediatric palliative care and describes the implementation of an interdisciplinary education program at his institution. He concludes that, "While more research is needed, a strong foundation has been established in support of a model of practice and education with innate ties to hospice and palliative medicine."

Three Steps to Counter Policy Misinformation in Pediatric Hospice and Palliative Care

p. 22

Lisa C. Lindley, PhD, RN, FPCN, FAAN, and Betsy Hawley, MA

"The purpose of this article is to share a case of misinformation and suggest three steps to counter it... Our case comes from pediatric concurrent hospice care. The misinformation presented is that Medicaid managed care plans do not need to offer or provide concurrent hospice care to their pediatric beneficiaries because they are in managed care...Misinformation can lead to children not receiving a Medicaid benefit they are entitled to, and ultimately not receiving quality end-of-life care." The three steps these authors recommend to counter misinformation are: Review the evidence; Involve internal and external resources; and Report the misinformation.

Pediatric Palliative Care Webinar Series

p. 24

Betsy Hawley, MA, Christy Torkildson, PhD, RN, PHN, FPCN, and Kristin James, LCPC

Three pediatric care coalitions from Pennsylvania, California, and Illinois "joined together in 2018 to develop a webinar series focused on pediatric palliative and hospice care. The goal of the PPC Webinar Series is to provide accessible, multidisciplinary pediatric education that addresses core learning needs as well as highlighting innovations for both advanced training and new-entry professionals. The PPC Webinar Series allows easy access to experts without adding travel time and expenses, or the cost of a full conference." This article describes the focus of the webinar sessions on "commonly requested topics and highly sought-after speakers who can share their expertise with a national audience" and provides additional information about the series.

Pediatric Hospice and Palliative Care Training for Pediatric Emotional Support

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Jessica Sturgeon, MT-BC

This article takes note of the important role that music therapy and art therapy can contribute to pediatric hospice and palliative care. From that perspective, the author explains how leading organizations in each of these disciplines have taken action to provide educational and training resources for their members. At the same time, she advocates for a collective effort "across the expressive arts community to offer more evidenced-based, comprehensive, and specific training as it pertains to pediatric hospice and palliative care."

Pediatric Palliative Care and the Social Work Role

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Stacy S. Remke, MSW, LICSW, APHSW-C

Although this issue is focused on education and training for pediatric palliative care providers, we realize that many do not fully understand the role/training/scope of practice for different members of an interdisciplinary team. This article is focused on the role of the Social Worker and we plan to do the same in future issues with different interdisciplinary team members.

Spiritual Care Education to Support Pediatric Palliative Care

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Judy Zeringue, MAPL, BSN, RN, CPLC, CHPPN

Another important dimension of interdisciplinary teamwork in pediatric palliative and hospice care is spiritual care. The author of this article advocates for such care by distinguishing between religion and spirituality, empathetic listening and compassion in serving those entrusted to pediatric palliative and hospice care, and identifying resources for spiritual care.

Becoming a Pediatric Hospice and Palliative Care Pharmacist

p. 33

Melissa Hunt, PharmD, BCPPS

Many professionals and volunteers look back on their journey and marvel at how exactly they came to be involved in pediatric hospice and palliative care. Few have experienced a more unusual and interesting path to this work than those in pharmacy. This author shares her history and her "first task in my new role was creating the reference I wish I had. I reviewed all the available pediatric hospice and palliative references I could find. I took everything I found valuable regarding symptom management and compiled it in one place: *The Pediatric Palliative Care Consultant: Guidelines for Effective Management of Symptoms*," a book now available from Amazon "designed to provide practical recommendations for palliative symptom management in pediatric patients. The aim of this guide is to equip all practitioners who care for pediatric patients with chronic life-limiting conditions, whether they have pediatric-specific training, or rarely see a pediatric patient." She describes this unique resource and its potential uses in the following ways: (1) "For those experienced in treating pediatric patients, this book may be used as a resource for support of current practice and a quick reference guide"; (2) "For those who only occasionally treat pediatric patients, this book may be used as a learning guide and a resource to ensure symptoms are appropriately treated"; and (3) "For educators, this book may be used as a training guide to address the basics of pediatric palliative care and assist learners in developing a comprehensive plan for symptom management."

Pediatric Palliative and Hospice Care Training & Educational Resources

p. 35

Compiled by Ann Fitzsimons, BS, MBA

This is an extensive compilation of a total of 19 resources, including for each a website address and brief descriptions, organized around 2 in-person trainings, 11 online training/educational resources, 3 perinatal hospice and palliative care resources, 2 pediatric palliative/hospice care webinar series, and 1 listing of pediatric palliative care coalitions.

Pediatric Educational Opportunities Provided by NHPCO

p. 40

Compiled by Amelia Emons.

This is a brief compilation of examples of some of the many educational resources available from NHPCO, with descriptions, learning objectives, and faculty for 3 webinars ("Where the Cellular Won't Roam," "What Adult Providers Need to Know to Care for Children," and "Cultural Humility in Pediatric Care").

Items of Interest

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Courageous Parents Network

Chrissy Salley, Ph.D.

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Courageous Parents Network (CPN) is a national nonprofit, 501(c)(3) organization that provides curated digital resources and programming to help parent caregivers advocate for their children living with serious illness and navigate the illness journey. Its mission is to orient and empower caregivers and others by providing them with resources and tools that reflect the experience and perspective of other families and clinicians. CPN's resources can be accessed via web and a mobile app. The resources offered are developed by parents and experts and can be used for educational and training initiatives. In this piece, we break down some options for educators from a range of disciplines to use to teach in their practice.

Clinician Portal

Clinicians, educators, and researchers are encouraged to connect with CPN in order to gain access to the Clinician Portal. Here you will find several resources for self-education and training.

1. **The Power of the Family Voice: 5 Packaged Teaching Modules.** These prepared mini-curricula can be adapted for 60- or 90-minute lectures and include learning objectives, selected videos, and discussion prompts to guide you in these didactic and discussion style lectures.
2. **Pathways.** Pathways are guided learning experiences on relevant topics including Delivering the Diagnosis or Bad News, Shared Decision Making, Spirituality, Supporting Families in Bereavement, Understanding the Lived Family Experience, and Advanced Care Planning. Each Pathway can be completed at your own pace and includes text, brief videos, and other resources to enhance learning and practical application of skills.
3. **Pediatric Palliative Care.** Palliative Care concepts that include introducing families to palliative care, can also be found in the clinician portal and are complementary to palliative care concepts resources that are open to families outside of the Clinician Portal.

Caregivers Resources as Educational Tools

Did you know that clinicians report one of the top reasons they visit CPN is to better understand the family experience? The resources developed by CPN for families can also be used in training and education. Here are just a few:

1. Videos Centering the Caregiver Experience. CPN has developed more than 600 short videos (e.g., 3-6 minutes) of caregivers and clinicians who speak on a wide range of topics. Videos on caregivers, siblings, and extended family can be added to presentations to bring concepts to life for learners who often benefit from hearing directly from families themselves.
2. Videos from Clinicians. Providers from diverse professions (physicians, nurses, social workers, psychologists, child life specialists, genetic counselors, and more) are represented. In these videos clinicians speak about their experiences working with families and model communication strategies, provide education, and describe their personal experiences caring for families.

Events

Each month, CPN hosts live, virtual events with expert and caregiver guests. Each event is dedicated to one topic that is carefully selected based on what we hear caregivers are wanting to hear more about. However, caregivers and clinicians are all encouraged to attend these educational learning experiences where questions and comments are encouraged. Providers frequently attend for their own education and to better understand the family experience.

Speaking Engagements

CPN staff frequently speak to groups at hospitals, conferences, patient organizations, and other relevant groups. With both parent and clinician speakers we can cover an assortment of topics such as the family experience, shared decision making, fostering good parent beliefs, meaning making, anticipatory grief, understanding clinical trials, and more.

For more information regarding Courageous Parents Network, assistance with finding a resource, or to schedule a presentation please reach out to Chrissy@courageousparentsnetwork.org

Center to Advance Palliative Care (CAPC) Education and Training Tools

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CAPC is one of the oldest multidisciplinary sources of palliative care educational material. Originally part of the Robert Wood Johnson Foundation, CAPC was formed in 1999, to improve the lives of people living with serious chronic medical conditions and those caring for them.

The CAPC pediatric palliative care (PPC) training guidelines were developed in conjunction with the PPC Taskforce of the National Coalition of Hospice and Palliative Care <https://www.nationalcoalitionhpc.org/pediatric/>. There are open access, downloadable training recommendations for physicians, nurses, advance practice nurses, physician assistants, social workers, psychologists, and chaplains who care for children with severe chronic medical conditions and their families. <https://www.capc.org/training-recommendations-pediatrics/>. Just so the pediatric provider who is a novice in the care of this population knows what she or he really needs to learn about, CAPC has training recommendations so that one is aware of all her or his educational needs. www.capc.org/training-recommendations-pediatrics/physicians/.

In addition to the educational resources, the “toolkits” focused on pediatric palliative care (PPC) on the CAPC website are very helpful in outlining aspects of setting up a PPC program and training the providers. Below are some examples of PPC CAPC toolkits, many of which are open access.

I. PPC billing and Business Planning: While this is targeted to those who plan and sustain programs, providers should be educated about financial aspects that allow programs to thrive. www.capc.org/toolkits/pediatric-palliative-care-billing-and-business-planning/

- A.** Covering costs and generating revenue: In addition to financing strategies, this includes information about Concurrent Care for Children. This government program allowing funding for concurrent curative and hospice care seems to many providers difficult to understand and put into practice. However for those organizations who embrace it, this support may help the organization thrive financially.
- B.** Fee for service billing practices (CAPC members only)
- C.** Staffing, budgeting, and business planning for PPC (members only)

II. PPC Delivery Toolkit www.capc.org/toolkits/designing-a-pediatric-palliative-care-program/

- A.** Foundational tools and making the case for PPC: There are downloadable tools including a field guide, making the case for PPC, putting PPC in “prime time”, and information about PPC leadership center
- B.** Program financing (members only): There is information on the basics of business planning, how to demonstrate value, and how to align the funding sources and program expenses.

- C. Standards and guidelines for PPC: This section is full of resources available on the web from well know sources such as the National Consensus Project for Quality Palliative Care (4th ed), the American Academy of Pediatrics (AAP) Commitments, Guidelines, and Recommendations for Pediatric Palliative Care and Hospice, The Joint Commission (TJC) Advanced Certification for Palliative Care, Optimal Resources for Cancer Care (2020 Standards), and the Pediatric Psychosocial Oncology Care Standards (2015).
- D. Program design: While most of this section is only available to CAPC members, there is a nice accessible section on the PPC practice as a medical home for children with medical complexity.
- E. Clinical tools: While the tools concerning referral criteria, decision making, pain assessment and management, and transition to adult care are accessible only to members, the AAP tool concerning online conversations on PPC best practices, My Wishes (Pediatric), and the NIH NINR Palliative Care Conversations Matter are all open access.
- F. Program staffing: This includes core competencies, models of staffing, and program design staffing worksheet and are all accessible to CAPC members only.
- G. Staff education: This includes links to information about EQIPP: Talking about Serious Illness developed by CAPC, the Courageous Parents' Network, and the AAP, EPEC-Pediatrics, Pediatric Pain Treatment and Opioid Prescribing, American Academy of Pediatrics (AAP) Online Curriculum: Resilience in the Face of Grief and Loss, and NIH NINR Palliative Care: Conversations Matter.
- H. Job descriptions: This sections is exclusively members only.
- I. Program marketing: This section includes comments by a clinical leader of PPC, NHPCO Brochures for Families, and a Pediatric Palliative Care At-a-Glance Fact Sheet. Available to members only are a sample PPC program brochure, a complex care team handout, and a services description handout.
- J. Program measurement: While the measurement of best practices and webinar on evidence as a tactic to advance PPC are accessible, the metrics and measurement overview, and satisfaction surveys for current patients, bereaved parents, discharged patients, and referring clinicians are members only.
- K. Resources for patients and families: This includes the English and Spanish versions of Palliative Care for Children: Support for the Whole Family When Your Child Is Living with a Serious Illness, Pediatric Palliative Care At-a-Glance Fact Sheet, Get Palliative Care: Pediatric Palliative Care, Perinatal Hospice & Palliative Care, Pediatric Palliative Care At-a-Glance Fact Sheet, and several other resources focused on the families of medically complex children.

III. Online courses www.capc.org/training/: There are online courses on acute and chronic pain management, symptom management, communication skills, advance care planning, relief of suffering, and whole patient care. Many are open access but most are not geared specifically toward children.

How might an interested professional caring for a child with medical complexity educate themselves about PPC using the CAPC materials? It depends....

■ Pediatric providers caring for the occasional child with medical complexity

- Seek help managing specific pain and symptoms
- Renew knowledge about decisional support and advance care planning
- Review communication strategies with both children and the family

■ Providers with moderate experience with medically complex children

- Familiarize yourself with available CAPC tools and educate yourself about best PPC practices
- Utilize the above tools appropriate to your patients
- Strongly consider joining CAPC

■ Specialist providers primarily providing PPC for children with medical complexity

- If you are not a CAPC member yet, you should join!
- Align your practice with the standards and guidelines
- Incorporate ongoing staff education
- Ensure that you, the staff, and your organization follow best practices and outcome measurements

■ Program managers

- Utilize resources about marketing, financing, business and planning, choosing those parts appropriate to the size and scope of the practice CAPC is a well-rounded resource for those involved in the care of children with medical complexity and their families. It is a powerful educational tool. While not all of educational material is open access, much is. And it is accessible by a touch of a mouse!

The Expansion of Pediatric Palliative Care Education: Where are We Now?

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Overview

Over the past two decades there has been substantial growth in the availability of pediatric palliative care (PPC) services in the United States (U.S.) and palliative care has increasingly become the standard of practice in caring for children living with serious illness. Nationally, the number of palliative care programs has steadily increased with most freestanding children's hospitals in the US now reporting having a PPC program (Rogers et al., 2021). Acceptance of palliative care as a recognized specialty provides a valuable resource for improvement of care across the lifespan and around the globe. Despite the increased growth of PPC in the U.S., there remains a constant demand for services, and availability of PPC is scarce at global levels. Children remain among the most underserved seriously-ill populations receiving hospice and palliative care throughout the world.

The recent COVID-19 pandemic wreaked havoc on healthcare systems and catapulted the value of palliative care and the importance of palliative care education. Now, more than ever, children living with serious illness and facing the end of their lives, their caregivers, and teams caring for them are acutely aware of the support needed during this challenging time. The future of PPC calls for purposeful approaches to creating pathways for accessing high-quality resources and educational initiatives. These resources must continue to support the child and family unit, in addition to paying careful attention to the community in which the child resides (e.g., school, religious

communities, teams, extracurricular activities, etc.). Primary or generalist palliative care should be delivered by all clinicians caring for children living with serious or life-threatening illnesses. To deliver this care effectively, widespread palliative care education should be integrated across all domains and specialties.

The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve end-of-life care and continues to be the gold standard in palliative care education. The project uses a train-the-trainer approach to provide nurses and other interprofessional team members with education in palliative and end-of-life care on topics including pain and symptom management, communication, ethics, care at the time of death, loss, grief, and bereavement, and self-care. ELNEC Pediatric was developed by pediatric palliative care experts and piloted in 2003 (AACN, 2023). To meet the needs of the evolving landscape of PPC, the ELNEC faculty is committed to answering the call for increased palliative care education. This includes increased ELNEC Pediatric course offerings, development of new and existing modules, and increased growth at the international level. This article summarizes this expansion over the last few years and describes what is on the horizon for ELNEC Pediatric.

Growth of ELNEC Pediatric

Creation of ELNEC Perinatal

Significant advancements in fetal care over the past several years have resulted in an increased call for palliative care services in the prenatal period. Advancements in fetal imaging have led to an ability to detect fetal abnormalities that were previously not known before birth. Fetal surgery allows for interventions for some conditions that historically had no treatment options available (Denney-Koelsch & Côté-Arsenault, 2020). Parents who learn their unborn baby has a life-limiting fetal condition (LLFC) require support and assistance with establishing goals of care and decision making. With an infant mortality rate of 5.4 per 1,000 live births, the perinatal period has the highest morbidity and mortality rates of pediatric patients (Xu et al., 2022). Approximately 2-3% of the near four million U.S. births per year present with a birth defect, and nearly 1 in 5 of these babies do not survive infancy (Denney-Koelsch & Côté-Arsenault, 2020). In response to these needs, perinatal palliative care services have experienced exponential growth across the United States over the past 10 years (Leuthner & Jones, 2020). The care of these babies and families is unique and requires specialized palliative care training.

In 2020, the ELNEC team expanded its education efforts to include perinatal palliative care in response to the needs of this growing population with the creation of ELNEC Perinatal. This curriculum is intended for nurses working with families in maternal-fetal medicine, fetal clinics, labor and delivery, nursery or NICU whose child may have a LLFC. The ELNEC Perinatal curriculum includes topics such as: key components of perinatal palliative care, communication strategies and techniques, establishing goals of care, creating a birth plan, care after the birth including management of symptoms, care after the death, ethics, and self-care strategies. The goal of ELNEC Perinatal is to prepare nurses to guide families through decision-making with a focus on maximizing quality of life and honoring family values and wishes during pregnancy. ELNEC Perinatal is a tremendous resource to this ever-expanding niche of healthcare.

ELNEC Pediatric International

A second significant area of growth for ELNEC Pediatric has been its expansion at the international level. Education is essential for nurses worldwide to properly prepare the global nursing workforce and provide holistic, person-centered care for children living with serious illness and their families throughout the care continuum (Rosa, Gray, et al., 2020; Rosa, Krakauer, et al., 2020). ELNEC faculty have been teaching internationally since 2006, with the first international ELNEC Core course held in Salzburg, Austria. Furthermore, ELNEC has expanded to 101 countries and the curriculum has been translated into twelve languages. In 2017, ELNEC Pediatric was launched in Kyoto, Japan, and other Asian Countries utilizing the train-the-trainer model. In addition to pediatric nurses, the need for additional interprofessional members of the team to be educated in palliative care has also expanded.

Since 2019, palliative care leaders from seven additional countries have participated in ELNEC Pediatric train-the-trainer course. These courses, attended by competitively chosen nursing leaders in education and clinical practice from Eastern and Central European, former Soviet Union, and Central Asian countries were also held in Salzburg as part of a larger group of nurses receiving ELNEC Core train-the-trainer education. By participating in train-the-trainer palliative care courses, learners are empowered to return to their home countries to share the learned information and disseminate the palliative care knowledge and skills to other nurses and team members. This teaching model is aimed at reducing barriers for nurses and other healthcare professionals caring for individuals with serious illness and to increase access to palliative care. The countries represented attending ELNEC Pediatric trainings in 2021 and 2022 included Albania, Armenia, Georgia, Greece, Hungary, Moldova, and Romania. Twelve nurse leaders from in-patient units as well as out-patient hospice organizations and one pediatrician were among the participants. Additional ELNEC Pediatric international train-the-trainer courses are scheduled for 2023 including courses in Albania, Austria, and Greece.

Future Work

ELNEC continues to meet the needs of nurses and other healthcare professionals seeking to increase their knowledge and skills in caring for children with serious illness and their families. Relevant and current issues must continue to be integrated into the curriculum. An example of this is the prevalence of mental health needs among youth today. The lived experiences of children should remain a core focus of PPC education given the increased risk of anxiety and depression in this population; children receiving PPC must continue to receive adequate mental health resources. This will require the creation of unique partnerships (e.g., medicine and psychology) to explore care models that ensure a holistic approach to meeting both PPC and mental health needs. It is also essential that psychologic resources must be embedded into all PPC education.

A well-known PPC nurse practitioner, Kathy Perko, MS, PPCNP-BC, CHPPN, CPON, CPLC, FPCN, FAPHON, serves as the Pediatric PC Certificate Track Director for the University of Washington. She reflected on the future of pediatric PC: "Palliative care skills are imperative to meet the needs of seriously-ill children; these include empathic communication and listening skills, symptom assessment throughout the palliative care trajectory, and access to a specialty team for support and consultation." Thus, there is a need to mentor new PPC providers, provide resources to support the development of new PPC programs, and ensure continued access to PPC, such as ELNEC. PPC training models that include interprofessional collaboration must continue to grow and expand to include non-pharmacologic resources such as music, art, play, and pet therapy. Moreover, there is a need to increase PPC training models for rural and underserved communities throughout the U.S. Likewise, global support for PPC training must continue to expand to allow access to virtual educational resources for nurses and other interprofessional team members in other countries. Cultivating a culture of support for high-quality PPC resources has taken some time, yet the benefits of change are evident and there is still progress to be made in the years ahead.

Conclusion

Palliative care continues to become the standard of care for children living with serious and life-threatening illnesses, thereby promulgating the need for more resources and specialized training in this area for nurses and other interprofessional team members in the U.S. and globally. ELNEC Pediatric is an international education initiative that has responded to this need using a train-the-trainer approach to provide nursing education in accordance with the changing healthcare landscape for more than two decades. Specialized curriculum in Perinatal Palliative Care was created to prepare nurses to support families in the context of significant advancements in fetal care and increased complexity in goal setting and decision making. ELNEC has also expanded its reach to over 100 countries with the goal of reducing barriers for nurses and other healthcare professionals caring for individuals

with serious illness around the globe, and many countries now offer ELNEC Pediatric specifically. As the future of healthcare evolves, it is anticipated that nurses and other healthcare professionals will continue to seek specialized education to increase their knowledge and skills in providing PPC and educational initiatives, such as ELNEC, will continue to meet this need through diverse and dynamic curricula.

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Education in Palliative and End Of Life Care (EPEC)-Pediatrics: Teaching Pediatric Palliative Care in a Virtual Setting Lessons Learned During the Covid-19 Pandemic

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Introduction

The Education in Palliative and End of Life Care-Pediatrics (EPEC-Pediatrics) program was developed to fill a void in pediatric palliative care (PPC) training and dissemination. The curriculum development was funded by a \$1.6 million National Institutes of Health/National Cancer Institute R25 grant (PI: Stefan Friedrichsdorf) from 2010-2017 with emphasis on training clinicians who care for children with serious illness. Since then, EPEC-Pediatrics has evolved and expanded in many ways with global accessibility at its core.¹⁻³ To date, we have trained 1,774 clinicians from 114 countries across 6 continents who are EPEC-Pediatrics Trainers (1,104), Master Facilitators (MF, 125), and end-users.

What is the Curriculum Content?

The curriculum is now comprised of 24 pediatric palliative care modules, delivered in a combination of online learning and in-person, face-to-face conference sessions. These "Train-the-Trainer" conferences provide the "Trainers" (pediatric clinicians) with all PowerPoint presentations, all trigger-tape videos, and a teaching handbook for each module for teaching interdisciplinary teams (Table 1).

The 3 Levels of EPEC-Pediatrics Training

- **LEVEL 1: End-user training.** This is basic (or advanced) training for interdisciplinary clinicians (e.g., physicians, nurse practitioners, nurses, social workers, psychologists, chaplains, administrators, etc.) who want to learn (but not necessarily teach) the content. This can be done for 10 or for 1000 people in one room, and we can teach just 1 module or all 24 modules, with or without breakout rooms. Participants do not receive the EPEC-Pediatrics curriculum teaching materials (i.e., PowerPoint presentations, videos, and teaching guides).
- **LEVEL 2: "Become an EPEC-Pediatrics Trainer" Conference:** This is what we offer most often. The participants of this course already have a background in PPC and attend this conference to learn how to teach the EPEC-Pediatrics Curriculum. After finishing all 24 training modules (through a 2-5 day face-to-face conference plus 18 online training modules) participants become "EPEC-Pediatrics Trainers" and will receive all teaching materials. EPEC-Pediatrics Trainers can then teach LEVEL 1 End-user training, either at their own home institution, a PPC training conference, or elsewhere.
- **LEVEL 3: Professional Development Workshop (PDW):** To become a Master Facilitator (MF), someone, who teaches new "Trainers" at LEVEL 2, one must be: (1) an EPEC-Pediatrics Trainer, (2) have participated in a EPEC-Pediatrics PDW (1-day course), and (3) have taught at a LEVEL 2: "Become an EPEC-Pediatrics Trainer" Conference as a junior-level MF under supervision and with feedback from a senior-level MF.

The EPEC-Pediatrics approach to teaching

Teaching how to teach: "Hook," "Attitude," "Knowledge," and "Skill"

A common mistake in medical teaching is the misconception that a large amount of knowledge (i.e., large number of PowerPoint slides during a presentation) will convince the audience to change their behavior (e.g., a physician will decide to administer morphine to a child with terminal dyspnea the day after hearing the talk). Unfortunately, this approach is ineffective, and Dixon (1978) postulated that, to change clinicians' behavior, and thereby patient outcomes, one needs to address attitudes and skills in addition to knowledge.

EPEC-Pediatrics creates Trainers and Master Facilitators

Teaching both Trainers and future MFs requires practice in adult teaching strategies under the supervision of senior MFs through experience and practice during an EPEC-Pediatrics conference. Key teaching modalities include: (a) interactive lecture, (b) role play, and (c) case study. Experience in medical teaching has shown that nothing is more likely to lose the audience's attention than a presenter clicking through far too many PowerPoint slides and reading from them in a monotonous voice without engaging the participants. EPEC-Pediatrics teaches Trainers and MFs to use an interactive lecture style with case examples and/or role play. We strongly discourage the use of too many slides and encourage making use of small group discussion, and/or facilitated discussion with all participants, use of flip charts, etc.

EPEC-Pediatrics during the COVID-19 pandemic

When the COVID-19 pandemic hit in early 2020, we witnessed what felt like the world coming to a grinding halt. Healthcare systems and services were overwhelmed by patient care demands, including increased demands for palliative and end-of-life care. Recognizing the widespread, growing need for PPC training, we knew we must get creative and think outside of the box by leveraging our existing resources, including strong global interprofessional collaborations developed through EPEC-P partnerships over the previous 10 years, to ensure delivery of advanced PPC training continued during a time of heightened need. The following article describes four key lessons learned from our experience ensuring that PPC education remained a top priority during a time of global crisis.

1. Virtual learning provides an opportunity to expand teaching skills and utilize new teaching techniques

For virtual learning to be successful and meaningful, the educational resources must be well structured, and the learning experiences must be intended to promote engaging interaction for learners through the online platform.^{4,5} While we all had some experience attending meetings through virtual platforms (Zoom, Teams, Webex), we knew that teaching PPC on a virtual platform using different modalities would require new/innovative approaches AND patience, humility, humor, flexibility, willingness to learn new skills from our peers, and time to teach our new and experienced MFs (training faculty) these skills.

In late 2020, we decided to plan our first global virtual EPEC-Pediatrics workshop with senior MFs from Latin America and the Asia-Pacific region. To prepare ourselves and our regional MFs to teach participants using Zoom, we sought out advanced training opportunities from clinical colleagues with advanced knowledge of virtual teaching methods for clinical learners. This included a course on how to adapt EPEC-specific teaching modalities that are typically more conducive to face-to-face delivery (e.g., role play) and a course on virtual medical education delivery using advanced Zoom-based teaching tools and techniques to engage learners. Both workshops were recorded and continue to be available for viewing. We are now making full use of different interactive modalities that were previously used in in-person training in an effort to encourage engagement by participants from around the globe. Some of these activities include: role play, use of virtual whiteboards, waterfall questions (i.e., "name one or two things you do to promote your own wellbeing," or "tell us one word that comes to mind when you think of grief"), poll questions, and QR code-scanning to access supplementary materials, making it easy to participate. These interactive activities have inspired group bonding in a friendly virtual environment, empowering learners beyond the traditional classroom setting.

2. Virtually, we are more diverse and reach a broader audience

The EPEC-Pediatrics leadership team was concerned about the loss of in-person interactions and networking that occurs naturally during in-person conferences. However, we were surprised by the number of new virtual communities that evolved as a result of the first virtual workshop. The Global EPEC-Pediatrics Workshop was held in March 2021 and was a success in many ways. The new "workshop" (end-user) format focused on early learners and, unlike the traditional EPEC-P Train-the-Trainer (TtT) model, the workshop placed less emphasis on teaching how to teach and more emphasis on teaching about PPC delivery. Our aim was to ensure a welcoming environment for an interprofessional group of participants, from nurses to social workers to hospital administrators who

represent different clinical areas of expertise (e.g., oncology, intensive care). We encouraged global attendance irrespective of ability to pay by implementing tiered pricing for clinicians from low- to low-medium income countries and a new scholarship program co-sponsored by both St. Jude Global Academy and University of California, San Francisco (UCSF). Because we knew many participants would be native Spanish-speakers located throughout Central and South America, we collaborated with the Latin American leadership team to host a live language translator. Attendees participated simultaneously across multiple geographic time zones for the plenary sessions, and regional MFs held breakout sessions at ideal local times.

Since the March 2021 global workshop, we have hosted 10 conferences (4 virtual; 4 hybrid), including pre-recorded, asynchronous lectures and a bilingual workshop with interactive lectures and small group sessions, which resulted not only in improvements in participants' personal PPC knowledge, attitudes, 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. The virtual EPEC-Pediatrics platform has allowed for the continuity of training of a global network of healthcare professionals and regional senior MFs (e.g., in South America, Canada, Southeast Asia, Australia/New Zealand, India, and Europe) to ensure ongoing training with little or no reliance on the U.S.-based core master facilitators.⁶

3. Teaching virtually requires an 'all hands on deck' approach

Hosting a live virtual conference can be challenging due all of its moving parts. We learned early on that successful virtual conferences require involvement from many individuals, including those behind the scenes to help ensure both students and MFs have continuous access to and support for the learning platform, are comfortable using its basic features, and are fully engaged. For example, MFs may take on multiple roles during the conference to encourage interaction during their colleagues' presentations, such as monitoring the chat box or encouraging participants to ask questions during a breakout room session. Non-teaching staff and/or duplicate teaching faculty must be available to provide other types of assistance, such as email monitoring to ensure there are no last-minute registration or remote access issues, live translation services, or virtual main room monitoring during breakout sessions to ensure participants joining late are able to join their assigned breakout room quickly. We have also prioritized inviting new, less experienced MFs from different geographic regions to teach at the virtual conferences to ensure cultural diversity, responsiveness, and enrichment.

4. Virtual learning has its limitations and barriers

Part of the learning process was evaluating the limitations and barriers to this radical change to our methodology. Some early barriers included providing too long of sessions at one time and difficulty in maintaining engagement. In the future, we also need to ensure that all participants are able to get the most out of the learning opportunity by adapting to different time zones and people's busy schedules. In hindsight, we should have made more effort to arrange for live Spanish-language translation after the first virtual conference, but the high percentage of native Spanish-speaker participants was not anticipated. In addition, it is challenging to track attendance/monitor engagement with the sessions as we can't force people to turn on their cameras. In 2022, we trialed a hybrid EPEC-P conference with a TtT track and an end-user workshop track, and both could be taken virtually or in person in San Francisco. We also offered a Professional Development Workshop (PDW) for in-person attendees. This proved challenging to administer from a logistical standpoint due to the need for additional human resources, audio-visual equipment, a stable internet connection, and clear backup plans in case something went wrong.

Summary and Future Steps

EPEC-Pediatrics is a state-of-the-art educational program that became even more accessible to global healthcare professionals through virtual learning. There is no turning back; virtual learning is here to stay. In May 2023, UCSF will host the 25th Become an EPEC-Pediatrics Trainer virtual Train-the-Trainer conference (<https://virtualce.ucsf>).

[edu/EPEC](#)) including the first-ever virtual PDW by adding new tools such as MURAL, Mentimeter, Padlet, Strawpoll, Jambord, among others. The need for increased pediatric palliative care education and training persists worldwide and across disciplines. The unanticipated consequence of the COVID-19 pandemic on PPC education has led to a wide array of opportunities for collaboration and increased accessibility for those in the farthest and most remote corners of the world who are eager to learn. EPEC-Pediatrics will continue to grow and evolve through virtual, hybrid, and in-person educational offerings. While we are excited to be able to offer in-person learning opportunities again, we will ensure the quality of virtual learning opportunities continues to improve, which will in turn improve the care of children and families with serious illnesses around the world. We look forward to helping our pediatric palliative care community grow as we all grow and evolve in our teaching techniques.

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Table 1: EPEC-Pediatrics Modules and Objectives

Module Title	Objectives
M1: What is Pediatric Palliative Care and Why Does it Matter: Palliative Care Overview	<ul style="list-style-type: none"> ■ Define PPC as a set of tasks ■ Identify predictable opportunities for palliative care intervention at different stages of disease ■ Describe when and how to utilize a subspecialty palliative care team ■ Evaluate myths and assumptions about PPC
M2: Child Development	<ul style="list-style-type: none"> ■ 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 utilized when working with children of diverse ages along the illness continuum and at end of life
M3: Family Centered Care	<ul style="list-style-type: none"> ■ Define Family-Centered Care (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	<ul style="list-style-type: none"> ■ 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

Module Title	Objectives
M5: Self Care for Professionals	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ Describe the 6 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ Review assumptions about opioid use in children ■ Evaluate the 4 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	<ul style="list-style-type: none"> ■ Review opioids commonly used in pediatric palliative care <ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> ■ Appreciate the high prevalence of neuropathic pain in pediatric palliative care ■ Define neuropathic pain and describe main causes in pediatric patients ■ Emphasize the role of opioids as a first-line agent in neuropathic pain management ■ Develop a step-by-step treatment approach for neuropathic pain, including pharmacologic (opioids, non-opioids, adjuvants), procedural and integrative medicine approaches
M13: Procedural Pain Management Strategies	<ul style="list-style-type: none"> ■ Describe the evidence for the importance of managing procedural pain ■ Review the 4 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*	<ul style="list-style-type: none"> ■ 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 <ul style="list-style-type: none"> - Opioids are usually not indicated! ■ 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

Module Title	Objectives
M15: Management of Gastrointestinal Symptoms	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ Describe how integrative medicine strategies can enhance care for children with life-threatening conditions. ■ Practice a relaxation and mental imagery (RMI) 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
M22: Introducing Quality Improvement in PPC	<ul style="list-style-type: none"> ■ 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 improving quality ■ Complete a performance improvement project
M23: Teaching Pain and Symptom Management	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ Review advantages and disadvantages of methadone use ■ Evaluate potential adverse effects of methadone ■ Explain difference of half-life compared to other opioids ■ Practice opioid rotation to methadone

[Included M24: Methadone* in the online version until 2016]

The Network of Pediatric Palliative Care Educators

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The Network of Pediatric Palliative Care Educators (NPPCE) launched in January 2022 with the goal of advancing access to quality interprofessional pediatric palliative care education through a community for collaboration and dissemination of educational best practices, research, and resources. The vision of NPPCE is to transform palliative care education through organization of an interprofessional community of educators, with the ultimate goal of improving care for children with serious illness and their families.

Having worked on educational research and scholarship as a pediatric oncology fellow at Stanford, Katharine Brock, MD, MS, recognized the need for assessment tools in pediatric palliative care education and simulation-based cases for teaching pediatric fellows about palliative care communication. She realized that faculty and clinicians likely had many educational projects on their computers that never made it to databases such as MedEdPORTAL. With the help of palliative care and simulation experts, she developed her own simulation-based communication curriculum that was piloted with pediatric hematology/oncology, cardiology, critical care medicine, and neonatology fellows. Since arriving to Emory University/ Children’s Healthcare of Atlanta as a faculty member, she continued to work on simulation-based curricula for residents and fellows, and later expanded to nursing curricula.

At the same time, Naomi Goloff, MD, saw the opportunity to create dedicated end-of-life (EOL) education for residents, fellows, nurses, social workers, and other clinicians working with children with serious illness which directly impacted their care as well as clinician wellbeing. Working together with simulation experts, as well as an interprofessional and interdisciplinary team at the University of Minnesota/University of Minnesota Children’s Hospital, she developed and piloted a simulation-based EOL care curriculum for pediatric subspecialty fellows, which later expanded to nurses and social workers.

In 2017, Katharine and Naomi were at the Pediatric Palliative Oncology Symposium at St. Jude. Katharine heard Naomi speak on her own educational projects over dinner. On the bus ride back to the hotel, Katharine shared an idea she was thinking about for sharing curricula and cases so that busy clinician-educators across the country

didn't have to keep reinventing the wheel. Surely, we were all trying to teach the same palliative care concepts and communication pearls. The two conversed about a far-fetched plan for a national group of pediatric palliative care educators to also help create a community.

Then, like so many stories, they both got busy and the idea just went back and forth in their inboxes...until 2019 when Naomi and Katharine asked Amy Trowbridge, MD, to join them. At the University of Washington/Seattle Children's, Amy had been working on many similar projects, including developing curricula in serious illness communication for medical students, pediatric residents, and pediatric subspecialty fellows. Additionally, as director of the Palliative Care Training Center at the University of Washington, she was developing a pediatric-specific Graduate Certificate Program for interprofessional clinicians looking to deepen their practice in both primary and subspecialty pediatric palliative care. She was the perfect addition to add momentum to the group.

The three NPPCE co-founders then formed an interdisciplinary advisory committee comprised of U.S. and Canadian-based physicians, advance practice providers, nurses, and social workers, including: Gitanjali (Tanya) Arora, MD, Jody Chrastek, RN, DNP, Sarah Friebert, MD, Jennifer Hwang, MD, Jenni Linebarger, MD, MPH, Arika Patneaude, LICSW, Stacy Remke, LICSW, Kyle Sue, MD, MHM, Camara Van Breemen, MN, NP, and Joanne Wolfe, MD, MPH. The co-founders and the advisory board honed the idea, mission, vision, schedule, and goals for the group.

And finally, NPPCE launched in January 2022, and so far has nearly 400 registered members! We completed one full year of programming and hosted an in-person gathering at the recently Annual Assembly in Montreal on March 23, 2023. NPPCE is open internationally to all types of interprofessional team members who teach pediatric palliative care. NPPCE hosts different types of sessions: Works in Progress or Educational Innovations, Best Practices in palliative care education, Spotlight on an educational method, and Interactive Educational Exchange. So far, the group has held sessions on Interprofessional Education, Family Engagement in Education, Improv in PPC Education, and Applying an Anti-Racist Lens to PPC Teaching, to name a few. The plan is to continue to hold every-other-month educational sessions and promote collaboration around educational projects. To obtain more information about NPPCE or to register, please visit the website (www.nppce.org).

Experiences in Pediatric Palliative Care Interdisciplinary Education

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One of the many reasons I am passionate about pediatric hospice and palliative medicine is the knowledge that the entirety of my career will be spent as both a student and an educator. Our field is young, growing, and tasked with a bold charge—the active total care of a child's mind, body, and spirit, and providing support to the patient's family.¹ When one considers the full continuum of a potentially life-limiting disease process in a pediatric patient—from diagnosis to (potential) death, inclusive of the spectrum of bereavement care—the scale of knowledge and experience required to adequately alleviate the various burdens patients, family members, and other caregivers may experience can be quite staggering.

Fortunately, we are not alone. Inclusive of physicians, nurses, social workers, chaplains, case managers, child life specialists, and many others spanning both the inpatient and outpatient realms, the proverbial village we are tasked to treat is supported by an equally robust team of professionals from a variety of disciplines, each with their own areas of expertise to assist in the care of patients, families, and other caregivers. Equally as fortunate, at almost no point in time throughout the illness trajectory does a team member need be treating a patient alone—adequate analgesia typically requires interventions directed at the physical, psychological, social, and spiritual domains²; alleviation of existential distress may require pharmacologic, spiritual and psychosocial treatment modalities; familial coping requires attention to prognostic understanding, grief/bereavement support, and a comprehension of social supports and family dynamics.

Hospice and palliative medicine is, by nature, an interdisciplinary field—a field in which two or more professionals of different disciplines work together collaboratively toward a common goal. Historically, the medical field has tended to be more multidisciplinary—many trainees honed their craft in relative discipline-specific isolation, later practicing on a team of individuals of multiple disciplines acting largely independently of one another, and with one person directing the team from a position of leadership. A multidisciplinary model of education and practice has been described as risking creation of "educational silos [which] can foster disciplinary distance,"³ leading to inherently segmented care. Such a care model is particularly maladapted to hospice and palliative medicine. "Body, mind, spirit and family are integrated in the patient and thus require the integrated and collaborative practice of an interdisciplinary team."³

Collectively, healthcare is recognizing the importance of an interdisciplinary model of care: the World Health Organization has acknowledged that interdisciplinary collaborative practice "strengthens health systems and improves health outcomes,"⁴ and that this care model "will play an important role in mitigating the global health workforce crisis."⁴ Such fluid, impactful interdisciplinary care requires an equally-fluid team dynamic, leadership structure, and collaboration archetype, relying upon mutually respectful recognition of—and arguably more important, understanding of—roles, experience, and expertise amongst team members.

Considering the diverse illnesses, disease trajectories, symptoms, and various psychosocial, emotional, and spiritual responses encountered in the patient and family populations served in pediatric palliative care, recognition that the

"expert" on any given interdisciplinary team is dynamic and often relative to a specific situation, patient, or family need³ likely doesn't surprise many of us. In my current practice, each of our team members lends an expertise that is wholly unique and indispensable to the quality of care we are able to collectively provide. And yet there is a learning curve to any fluidity with which we practice, as well as an ongoing, teamwide recognition that this learning curve will reset somewhat from time to time—as one team member incorporates a new skill into practice, other team members must learn and adapt their own practice in support of another's evolving skillset. Quality interdisciplinary collaborative care requires a commitment to ongoing interdisciplinary education—a deliberate, recurrent emphasis placed upon not just learning about one another, but also from and with one another—with the ultimate goal of training a "collaborative practice-ready health workforce that is better prepared to respond to local health needs."⁴

The concept of interdisciplinary team practice as a skill that can be learned,³ rather than spontaneously arising from experience, may surprise some. Our team was fortunate to be able to participate in the Interprofessional Education Exchange Project (iPEX, University of Louisville), which assisted the development of our interdisciplinary pediatric palliative care educational curriculum. Exposure to the ideas and creativity of our educators and other participating institutions shifted our approach to learner education from multidisciplinary to interdisciplinary. As we were implementing those changes, we recognized that we could apply similar methodology to our team dynamic.

Interdisciplinary team practice requires interdisciplinary education, defined by the World Health Organization as occurring "when students from two or more professions learn about, from and with each other."⁴ Historically, most interdisciplinary practice methodology has been learned on-the-job, following more traditional discipline-specific training.⁵ While some of this learning can take place innately, our team has found we are most effective as both learners and as educators when educational opportunities are formalized to include didactics, experiential learning, and finally either skill utilization, or taking an appropriate level of institutional "ownership" of the skill. We protect time at team meetings to learn an overview of a new topic or skill that a team member is incorporating into their practice, as well as when and how to trigger the utilization of that skill in our day-to-day practice. Following that meeting, we set aside time to collaboratively experience the skill as demonstrated by our team "expert" in a real-time encounter. We then solidify our knowledge of that skill by teaching its overview to rotating learners and hospital colleagues (creating a sense of teamwide expertise, with the team members who utilize the skill maintaining relative leadership positions) and/or incorporating the skill into our discipline-specific palliative care practice (if appropriate).

For example, we implemented a Pediatric Palliative Care Social Work Assessment tool approximately a year ago. Prior to implementation, our social workers taught the rest of our team the purpose and structure of the assessment; how best to explain its intent to patients, families, and colleagues; and described scenarios in which it could be appropriate to enact this tool. Following the didactic, we observed one or more palliative care social work patient encounters and participated in a post-encounter review to learn how this tool was effectively utilized. We then incorporated the tool into our interdisciplinary educational program for rotating learners, educated hospital colleagues, began to collaboratively round on patients partaking in this assessment as appropriate, and advocated for its utility in various team metrics. Other examples we have approached in a similar manner include advance care planning conversations initiated by a patient-facing case manager, a variety of hospice collaborative efforts, psychosocial list runs, and scheduled team didactics facilitated by alternating team members, among others.

Interdisciplinary education is supported by the National Consensus Project for Quality Palliative Care,⁶ and its impact on patient outcomes⁷ is well-substantiated in the published literature. While emphasis on interdisciplinary education amongst our own team has certainly changed the quality of care we provide and the comfort level with which we practice together, and likely our overall team efficiency, there is an argument that interdisciplinary education is perhaps most effectively implemented at the trainee-level that holds significant merit. Interdisciplinary education of trainees is supported by multiple institutions and was cited in a 2021 study supporting an interprofessional postgraduate pediatric palliative care fellowship program as effective in preparing clinicians for future interdisciplinary, collaborative practice.⁸ With these in mind, our team has coordinated the educational experiences of our rotating learners across multiple disciplines (social work, clinical pastoral education, medical) and training levels (students, residents, and fellows) through various organized, interprofessional interactions—including collaborative rounding, reflective writing exercises, monthly interdisciplinary case conferences, cross-training experiences, and shared didactics evaluated with a pre-/post-rotation assessment strategy—with the aim of magnifying the interdisciplinary nature of pediatric palliative care.

It should be recognized that our team's model is specific to our institutional resources and needs—other programs around the world have created very robust programs from which we can learn (and have learned) much. The World Health Organization recognizes that the “mechanisms that shape [interdisciplinary] education and collaborative practice are not the same in all healthcare systems”⁶, and cites supportive management practices; identification and support of champions; a resolve to change attitudes and culture; and a willingness to renew, update, and revise existing curricula to be effective mechanisms to help shape interdisciplinary education and practice.⁴ Interdisciplinary education can occur on a multitude of levels—amongst trainees, as amongst one team with members from various disciplines, or between different teams, among others—and requires an institution-specific approach depending on resources and needs. An emphasis on experiential learning, requiring “purposeful integration and collaboration among the disciplines,”⁹ is key.

Interdisciplinary palliative care education is becoming more widely discussed in the published literature, with a variety of resources available to assist with programmatic structuring and guidance. There are, however, some notable limitations. There is a paucity of interdisciplinary education evaluation tools available.¹⁰ As mentioned earlier, while interdisciplinary education can improve patient care, a position regarding the effect of interdisciplinary team practice on palliative care delivery remains lacking. Most available studies have been conducted in University health systems, with community-based systems comparatively underrepresented.⁸ Similarly, few studies address cultural aspects of interdisciplinary practice or education, its impact on well-being of the care team, or the sustainability of such programs.⁸ While more research is needed, a strong foundation has been established in support of a model of practice and education with innate ties to hospice and palliative medicine.

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Three Steps to Counter Policy Misinformation in Pediatric Hospice and Palliative Care

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Misinformation is a common problem in health care today. While misinformation gained prominence during COVID-19 with falsehoods, rumors, and inaccurate information, it is still with us. In fact, misinformation is not new to pediatric hospice and palliative care. How often have we heard patients and families say that hospice is giving up on the patient or hastening their death. Your communication toolkit probably already includes a range of responses to these inaccurate statements. But what about current attempts at misinformation in pediatric hospice and palliative care. Are you ready? The purpose of this article is to share a case of misinformation and suggest three steps to counter it.

Our case comes from pediatric concurrent hospice care. The misinformation presented is that Medicaid managed care plans do not need to offer or provide concurrent hospice care to their pediatric beneficiaries because they are in managed care. This statement has been repeated in multiple states over the past two years. If you are new to pediatric hospice and palliative care or an adult hospice providing care to a child, that might seem reasonable. You might not know the details of the benefit or how your state administers concurrent care. You might expect that groups such as a Medicaid managed care plan would know the federal and states laws about pediatric concurrent hospice care. And yet, something should tell us that this statement does not sound true. If it does not ring true, do not stop there. Take the next step. Misinformation can lead to children not receiving a Medicaid benefit they are entitled to, and ultimately not receiving quality end-of-life care. Steps to counter misinformation are:

Step 1 – Review the evidence

As clinicians, we review clinical evidence, protocols, and standards before making complex healthcare decision about children. The same applies to policy. Gather your evidence. Start by reviewing the federal law. In our case, does the federal law (ACA, Section 2302) state any exclusions related to managed care? A quick look will tell you the answer is no. Your next step is to review state and local documents for evidence such as your state Medicaid Hospice Manual. Are there exclusions to concurrent care for managed care beneficiaries in the state plan? As an example, the 2021 Missouri Hospice Manual includes information on both pediatric concurrent care and managed care plans. In this example, there is no mention of managed care exclusions in the concurrent care for children section. In addition, the

managed care section includes specific information about PROVIDING concurrent care for children. It states that children under 21 years on Medicaid managed care plans may continue to receive curative treatment services while enrolled with a hospice. In this example, if a Missouri Medicaid managed care plan provided misinformation about concurrent care, the evidence from federal and state documents counters that misinformation. Responding to misinformation might include a direct statement back to the person or group such as:

The Concurrent Care for Children benefit must be available to all children covered by Medicaid/Children's Health Insurance Plan (CHIP). As such, children enrolled in managed care plans, prepaid inpatient health plans, prepaid ambulatory health plans, primary care case management systems are entitled to the same Concurrent Care for Children benefit as fee-for-service beneficiaries.

Step 2 – Involve internal and external resources

In the event such misinformation is applied to children, their care is potentially compromised. A denial for concurrent care services for managed care children could result in a spiral of negative consequences from confusion about payment responsibilities to confusion about plan of care. Notifying internal resources including hospice and palliative team members, billing, and government affairs might ensure that everyone within your organization is aware of the facts and how to counter misinformation in your organization. Additionally, notifying external resources such as state advocacy groups or coalitions might offer new ideas for countering misinformation and building a common defense against false information.

Step 3 – Report the Misinformation

Another option to countering misinformation is to report it. Report this behavior to appropriate authorities whether that be your state Medicaid Quality Assurance hotline or your state Medicaid Administrator for hospice plans or managed care plans. In many cases, state Medicaid Administrators know very little about specific benefits such as concurrent care. They depend on accurate information from sources caring for Medicaid beneficiaries. Reporting misinformation can improve awareness, but also ensure that benefits for children are compliant.

The clinical care of children at end of life is complicated enough; encountering policy misinformation makes it more difficult. Using these three steps to counter policy misinformation can be applied to other occurrences of misinformation and not just concurrent hospice care. These steps offer clinicians and advocates tools for their toolkit in providing ongoing quality care that is compliant with state and federal law. While we hope that these three steps can be followed when encountering any medical misinformation, if you need more specific information about pediatric concurrent care including help with accurate state specific information and resources, please go to the Pediatric End-of-Life Care Research Group website (<https://pedeolcare.utk.edu/>).

Pediatric Palliative Care Webinar Series

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The number of children with chronic, complex, and life-limiting illness continues to increase, yet, less than 1% of children who could benefit from palliative care actually receive it. While we cannot change a child's prognosis, we can change how we care for them. One large barrier continues to be access to care. Adult providers, family practitioners, and hospice teams consistently identify training as one of the leading barriers to their ability to care for seriously-ill children. Even as the number of hospital systems with pediatric palliative care teams has grown, they often struggle to find time for education or funding to support professional development. There continues to be substantial data highlighting the workforce shortage in pediatric palliative care.

To address this need, Children's Hospice and Palliative Care Coalition of California, Greater Illinois Pediatric Palliative Care Coalition, and Pediatric Palliative Care Coalition of Pennsylvania joined together in 2018 to develop a webinar series focused on pediatric palliative and hospice care. The goal of the PPC Webinar Series is to provide accessible, multidisciplinary pediatric education that addresses core learning needs as well as highlighting innovations for both advanced training and new-entry professionals. The PPC Webinar Series allows easy access to experts without adding travel time and expenses, or the cost of a full conference. Recordings can also be used to view at a time convenient to the individual or team. The one-hour sessions also allow bite-sized learning and can be incorporated into team-based activities.

This series focuses on commonly requested topics and highly sought-after speakers who can share their expertise with a national audience. This collaboration allows for more efficient use of resources and shared talents. However, as the demand and interest in the series has grown, funding is needed to support additional administrative costs. The Coalition partners have currently been providing their time and expertise on an in-kind basis. In order to continue this valuable series, a more sustainable funding structure is needed.

Snapshot of the Pediatric Palliative Care Webinar Series:

1. 10 webinars featuring nationally recognized experts per year
2. Interdisciplinary topics ranging from specialized pain and symptom management to spiritual care and family resilience
3. Yearly attendance averaging 3,000 individuals from over 250 organizations across the country
4. Attendees include nurses, social workers, chaplains, physicians, and expressive therapists; as well as families and students representing both hospital and community-based organizations

5. Low pricing for individuals and group participation, subscription pricing available; scholarships available
6. Free for parents, caregivers and their families
7. Framework for webinars to be used as a team meeting to allow additional discussions, debriefings, and case reviews
8. Continuing Education available for nurses, social workers, and expressive therapies.
9. Option to participate in the live session or view the recorded session at a time convenient for participant or team
10. Access to library of archived recorded webinars for individual and team training

Comments from participants:

- "This webinar was stocked full of very practical ideas and helpful information to assist me in having difficult conversations with families!!"
- "This webinar provides practical guidance that I can use with my patients in need of transitional services."
- "The webinar will assist me in better supporting families and children during end-of-life and has helped me understand the impact of spirituality on terminal children."

To learn more about the Pediatric Palliative Care webinar series, view the calendar of upcoming sessions, or to register, please visit www.ppcwebinars.org

If you have any suggestions for topics or speakers please send them to us at the emails noted above.

Pediatric Hospice And Palliative Care Training for Pediatric Emotional Support

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Access and utilization of complimentary and expressive therapies continue to grow as the world of pediatric hospice and palliative care (PHPC) continues to expand nationally. To meet this ever-developing demand, additional opportunities for education and practice have erupted across all disciplines to better support the emotional needs of pediatric patients. Education and training can be accessed in known PHPC networks in addition to individual professions.

Two notable interdisciplinary group disciplines, music therapy and child life, have garnered a strong hold in the PHPC community due to their existing paths in hospital and home settings. Both disciplines offer the innate opportunity to access a child's emotions and provide opportunity for expression and effective coping. Generalized hospice and palliative care training can be completed through coursework and clinical placement for both music therapy and child life. However, there is limited educational access for these specific disciplines to PHPC outside of potential learning opportunities at conferences, through webinars, or networking. Often, professionals must rely on their connections to other PHPC clinicians and the limited PHPC-specific research that is available. Despite this, each field has been able to establish some connection to the clinical training needed to work in such a specialized field.

Music Therapy

Music Therapy has become an integrated member of the interdisciplinary group for hospices throughout the country. The benefits of music therapy have been backed by evidenced-based research and practice for decades with notable impact on a patient's quality of life, pain, anxiety, and emotional distress. In hospital systems, music therapists have become more integrated in treatment teams as continuing research displays efficacy decreasing hospital stays and offering procedural support in addition to the aforementioned. As PHPC can be utilized in both environments, there has been a great call for training to better serve the needs of children navigating life-limiting illness and their siblings, family, and friends. The Association for Music Therapy (AMTA) has provided access to ongoing research and information in the field to music therapy professionals with their journals, *Journal of Music Therapy and Music Therapy Perspectives*, and continuing education through <https://www.musictherapy.org>.

The Center for Music Therapy at End of Life has become a staple in the music therapy community to better offer training specific to hospice and palliative care. The hospice and palliative care music therapy (HPMT) certificate offers four separate training courses that provide "dynamic educational experiences that will prepare them to serve people with advanced illnesses and their families through the continuum of end-of-life and bereavement" (Center for Music Therapy at End of Life, 2023). The inclusion of materials specific to pediatrics at end of life and bereavement promotes the utilization of music therapy in the PHPC field while simultaneously providing opportunities for practice and implementation under expert supervision. More information on class schedules and course descriptions can be found at <https://www.hospicemusicaltherapy.org>.

Child Life

As the Association for Child Life (ACLP) notes, “child life specialists are trained professionals with expertise in helping children and their families overcome life’s most challenging events” (ACLP, 2023). As PHPC community-based programming becomes more accessible, there is an irrefutable need for child-based supports to be available to children and their families as they come to navigate life-limiting and terminal illnesses. Though child life has become the expectation of care in the hospital system, this exceptional child-centered support continues to grow its foothold in the community hospice and palliative care world. To further the engagement of child life in the home-setting, the ACLP has developed strong resources for its members including webinars specific to pediatric hospice and palliative care. The development of *The Journal of Child Life: Psychosocial Theory and Practice*, the ACLP Bulletin, and the #childlife blog have provided members of the profession more access to these topics.

Child life education and training provides the opportunity to learn and practice varying methods to access a child’s needs, meet them in a developmentally appropriate manner, and deliver an effective approach that can minimize suffering and enhance expression and understanding. In pediatric hospice and palliative care, this approach is vital as children learn how to navigate their “new normal” while further processing the changes in their bodies. With siblings, child life affords the opportunity to feel included and valued in a world where they may feel forgotten. Additional training in hospice and palliative care is essential to provide the best care for children. Coursework and on-site training are the two most accessible forms of training for child life in the world of PHPC and can often be found at well-known children’s hospitals and through regional child life groups found at <https://www.childlife.org/professional-development/related-events/regional-child-life-groups>.

Continued work can be done collectively across the expressive arts community to offer more evidenced-based, comprehensive, and specific training as it pertains to pediatric hospice and palliative care. Often, those in the field define their interest as a calling with many hearing the joyful noise of serving this population. As access and understanding grow about pediatric hospice and palliative care, so will the training to serve the emotional needs of such beautiful souls.

Pediatric Palliative Care and the Social Work Role

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Each pediatric palliative care (PPC) team needs a social worker. The impact of serious, life-threatening illness in childhood affects every member of the family, and pressures often endure over a significant period of time. Social workers in pediatric palliative care can be considered the family support professionals on the team, linking families to necessary practical assistance, emotional and psychological support, and engaging the systems of care to work together to better serve the child and family over time. Social work practice focuses on understanding systems—individuals, families, health care, communities, and society to name a few—and engages in activities that span boundaries and create connections to support care.

There is movement in the field to underscore that Palliative Social Work is an advanced practice, similar to, and also distinct from, the work many of our Social Work colleagues do on the inpatient service and in the community. In large part, this is due to the way social work roles have evolved as the specialty practice of palliative care has grown. Many hospital-based roles include well-understood functions like discharge planning and practical assistance, of course. Yet social workers at the Masters level, and especially those with independent counselor certification (LICSW or LISW, etc., depending on the state) can independently screen for, diagnose, and treat mental health conditions. Social work training (MSW) and practice is distinct from chaplain, psychology, and counselor training in several important ways. Perhaps most importantly social work examines and intervenes with the person in the context of their life, circumstances, strengths, needs, and vulnerabilities. We see the domains of practice as including situational and contextual interventions. We explore and facilitate the complex system that includes the patient/family circumstances, often times with interventions in the system of health care itself. It is important to understand it is not possible to separate the wellbeing of the person from these contextual factors. All this is to underscore that those without a SW degree may not have this same intentional perspective and professional focus. As a mentor once said, "not all problems are in one's head, yet they affect us there!" This reality has been highlighted in recent years as we observe, better understand, and confront the impact of social determinants of health, structural racism, health inequity, trauma, and the impact of serious childhood illness on the child, family, caregivers, and team.

Social workers in palliative care have been concerned for quite some time that our role and scope of practice are not well understood within our field, even amongst other health social workers. The mental health support and intervention provided by social workers on the team needs to be in the context of dynamic service delivery, many situational challenges, and circumstances that are quite different from classic counseling dynamics. Providing care in the context of serious illness also requires flexibility and a certain comfort level with the intensity of the work, as well as a working knowledge of child development, family systems, grief, loss, and trauma. Familiarity with various illness trajectories and impacts of treatment allow us to help families plan and manage the many pressures they face. Just like in any other area of practice, the more one engages in it, the better one often becomes. Expertise evolves from experience. While many health social work job descriptions are often very similar to those of the PPC social work, the opportunity to develop this kind of more focused expertise and the engagement with the teamwork involved with PPC service delivery are what set the PPC social work practice apart. Continuity of social work care for the child and family is also essential. Collaboration among unit-based or service line (i.e., oncology, ICU) social workers and PPC social workers is important as the child's condition and family needs change over time in both predictable and unexpected ways. The needs are always complex and always unique.

Because social workers pivot and adapt activities to the child, family, team, and community context it can sometimes be a challenge to understand the role. Different days practice can look quite different. Assessment of strengths, needs, vulnerabilities, and resources should be standard. In addition, referrals for practical assistance, provision of psychoeducation and anticipatory guidance, individual and family counseling, processing goals of care discussions, and interventions with the system of care itself are frequent social work activities within palliative care (Remke & Schermer, 2012). Social workers can provide a range of services and interventions aimed at strengthening families in their capacity to be effective partners with the health care team as they advocate for their children.

Some teams and systems have re-named clinical social work positions in palliative care to reflect the mental health emphasis and validate the advanced credentials desired for the work. Some examples include Clinical Social Worker, Palliative Mental Health Counselor, and Care Navigator. These titles often intend to differentiate the role from inpatient social work practice for various reasons. Some areas also experience a shortage of advanced practice social work candidates, so options have, of necessity, been explored. Some examples include using Mental Health or Marriage and Family Counselors emerging in what have historically been social work roles.

PhD psychologists and MA level counselors can bring many wonderful skills and abilities to the team, of course. It would be best if decisions could be made based on a good understanding of the roles and differences among the professions. It is worth noting that clinical social workers in fact provide most--over 60%--mental health services in the U.S. Social workers at the Masters level are the mental health experts on the palliative team. By being embedded within the palliative team itself the social work practitioner is in a good position to adapt and shape supportive interventions around child and family needs and evolving circumstances.

Recently competencies for pediatric palliative social work practice were published for the first time (Jonas et al., 2022a). We anticipate these will assist teams and planners as they make decisions about team composition and program development. There is now also an exam-based credential for social work practice in hospice and palliative care: the APHSW-C certification (APHSW.Org). The hospice and palliative care social work community is represented by the Social Work Hospice and Palliative Network: SWHPN.org. It is our hope stakeholders will all support, even expect, hospice and palliative care social workers to obtain this level of certification to help us ensure high quality, well-informed services for children and families, and to validate the advanced nature of this rich practice area. We urge organizations to invest in the professional growth and development of their palliative social workers, and to advocate for well-prepared and competent social work team members.

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Spiritual Care Education to Support Pediatric Palliative Care

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Spiritual care is an important aspect of total patient/family/caregiver care. "It is as important for health care professionals to talk with patients (family/caregiver) as it is to address the physical aspects of care."¹ It is important to consider the difference between Spirituality and Religion. Spirituality is a much broader concept. It may be thought of as a person's search for meaning in their lives and purpose. These people may find strength and hope in relationships or nature, just to name two. Religion may or may not be a component based on the individuals' beliefs and that which brings meaning or purpose to their life.

Spiritual care is about being honest, sincere, and authentic. It involves permitting our compassionate humanity to impact another in need. "Religion is one way, one very important and significant way, that we express our spirituality."² Spirituality may be expressed in many different ways. Perhaps through the beauty of nature, the joy of hearing a child's laughter, the gentle touch of shaking hands or offering a hug, and praying or sitting attentively in silence with one experiencing grief. All are unique means of experiencing our unique spirituality. "Beyond religion, with all that it offers some people, there is the broad sense of spirituality or faith that is an outgrowth of one's beliefs about life."³

There are many religions in the world, each bring their unique beliefs, rituals, and practices to consider with impending death and after death. These beliefs may impact health care decisions as well as considerations at time of death and bereavement practices. An understanding and openness to learn with cultural humility is what is important to support a patient/family/caregivers' beliefs, meeting them where they are and supporting them throughout their journey. If they desire a specific ritual or sacrament, we may offer to facilitate contact with their specific faith leader through our Chaplain. Respect this sacred time with compassionate presence and dignity for those served.

The NCP (National Consensus Project) defines spirituality as a "Dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred."⁴

As clinicians, an important skill set to develop is refraining from judgement and being open to those entrusted to your care. Empathetic listening and compassion can be a source of hope and strength in even the most difficult moments. Leaning in with sincerity and presence is often a vital link in rapport building and trust. Providing empathetic listening, being attentive and present to patients/family/ caregivers demonstrates compassion. If desired by a family, share in prayer to meet the specific needs to provide comfort and hope. Be attentive and respect the beliefs of those you serve with great compassion.

Spiritual care should be an important assessment performed on all patients, on admission and throughout the illness journey. "Although some may experience spiritual distress, others may have a spiritual transformation or experience spiritual growth and health."⁵

An individual's faith is based on their unique inner strengths and may be as distinct in meaning and value as every individual who holds this concept within. "Spiritual care concerns the total person and recognizes the interdependence and connectedness of mind, body, and spirit. It provides a dynamic resource for healing and wholeness by paying attention and responding to the unique needs, goals, and resources of each care recipient."⁶

Research has demonstrated how nurses trained in spiritual care can help identify a patient/ family/caregiver's need for spiritual support. Such nurses can assist in incorporating spiritual support into the care plan and collaborating with spiritual care providers.⁷ Spiritual support is essential in providing holistic care and serving those entrusted to our care with respect and dignity.

Some educational opportunities are provided below for professional growth in spiritual care. ISPEC- Interprofessional Spiritual Care Education Curriculum (ISPEC- Peds)

<https://smhs.gwu.edu/spirituality-health/program/transforming-practice-health-settings/interprofessional-spiritual-care-education-0/>

Relias Academy offers (ISPEC) ONLINE COURSE

Spiritual education offered through **SCA- Spiritual Care Association.**

<https://www.spiritualcareassociation.org/>

<https://www.spiritualcareassociation.org/education.html/>

Important Information About the SCA Learning Center

- The Online Learning Center uses a state-of-the-art learning management system
- Earn a certificate of completion and continuing education hours for each course completed.
- The price for Self-Guided Courses is \$145 for SCA members and \$345 for non-members.

SCA offers two Palliative Care Certificate Courses to help you deliver quality spiritual care to palliative care patients. Allow 6 months to complete.

Fundamentals of Spiritual Care in Palliative Care: 30hrs

Advanced Practice Spiritual Care in Palliative Care: 25hrs

The Center to Advance Palliative Care (CAPC) is another great source for educational information, including many resources which support spiritual care. www.capc.org/search/?q=Spiritual+care+education/

A Prayer for God's Children

Dear Heavenly Father,

We know you are here with us, that you surround us with your love and grace.

You give a sense of peace and hope, which can only come from You.

God of love, ever caring, stand by us in our times of need. Be our hope and bring us peace.

Watch over your beautiful children and grant them your mercy, healing, and strength.

Help us to trust in You, knowing with full confidence, you have a special plan for each of us.

Keep us strong in faith, hope and love. Guide those entrusted to provide care and support.

Give us courage and strength to support and bring hope and love to your beautiful children and their families. Your children are precious in your sight and beloved to all who know them.

All these things we humbly ask through Christ Our Lord, Amen.

*"Let the children come to me, and do not hinder them;
for to such belongs the kingdom of God."*

—Luke 18:16

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Submitted to NACC for World Health Day 2022

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Becoming a Pediatric Hospice and Palliative Care Pharmacist

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Pediatric Clinical Pharmacist
Optum Hospice Pharmacy Services
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During residency one of my favorite rotations was hematology/oncology. In addition to a couple of concentrated months with the team, I also rounded with them on the weekends, allowing us to develop a stronger relationship. The patients were on specific protocols, so the pharmacists didn't typically provide major recommendations regarding chemotherapy. But pharmacy was able to provide significant recommendations for general management, pain, TPN, etc. As a new pharmacist, I enjoyed the impact I was able to provide. I even considered completing a specialty residency in pediatric oncology. Ultimately, I decided not to further specialize (I thought pediatric pharmacy was specialized enough) and took a position as a clinical specialist in a pediatric intensive care unit (PICU) following residency (about seven hours from home).

The Women's and Children's Hospital where I worked was in between two larger children's hospitals (about an hour and a half in different directions). We had many "regulars" with chronic complex conditions that were frequently admitted to the PICU and discharged home straight from the PICU once they returned to baseline (due to complexity). In retrospect, these patients should have been followed by a palliative care team. But I don't even know if the Women's and Children's Hospital had a palliative care team at the time. If there was, I'd never seen them consulted and had not made their acquaintance.

Once my husband and I had children, it was more challenging to live so far from family. I wasn't actively looking for a new position, but we decided we'd be open to the possibility. When we randomly ran into a former colleague, she shared she was trying to find a replacement for herself. She had been in a part-time, work-from-home position in pediatric hospice for just a short time. I was intrigued because it sounded like the perfect position for me. Plus, it would allow us to move closer to family without the stress of coordinating job changes and house selling/buying in different states at the same time.

During discussions with the Optum team, I quickly realized this position would allow me to expand on my strengths while serving the most vulnerable pediatric patients. Also, they were able to justify transition of the position from part-time to full-time. I'm still amazed that the leadership saw the need for a pediatric trained pharmacist to better serve these vulnerable patients, despite the lack of patient volume. I don't take it lightly that the income I bring in for the organization will never cover my salary, but they continue to support me on the team because they know it's what right for their patients.

Unfortunately, palliative care wasn't a rotation during my pharmacy residency. Palliative care wasn't even a focus during pediatric pharmacotherapy board-certification. Honestly, it's rare for pediatric pharmacists to be involved with palliative care, let alone hospice. Often the oncology pharmacists step in when necessary. While there is excellent pediatric pharmacy training available, and superb palliative pharmacy training, there isn't adequate pediatric palliative pharmacy training offered. My palliative care training has been a compilation of adult palliative care pharmacy, pediatric multi-disciplinary training (not pharmacy specific), and significant independent research.

The first task in my new role was creating the reference I wish I had. I reviewed all the available pediatric hospice and palliative references I could find. I took everything I found valuable regarding symptom management and compiled it in

one place. With the help of three knowledgeable editors, the book has now been published as: *The Pediatric Palliative Care Consultant: Guidelines for Effective Management of Symptoms (PPCC)* (or *PediGEMS* as I lovingly refer to it).

PPCC was designed to provide practical recommendations for palliative symptom management in pediatric patients. The aim of this guide is to equip all practitioners who care for pediatric patients with chronic life-limiting conditions, whether they have pediatric-specific training, or rarely see a pediatric patient.

- For those experienced in treating pediatric patients, this book may be used as a resource for support of current practice and a quick reference guide.
- For those who only occasionally treat pediatric patients, this book may be used as a learning guide and a resource to ensure symptoms are appropriately treated.
- For educators, this book may be used as a training guide to address the basics of pediatric palliative care and assist learners in developing a comprehensive plan for symptom management.

PPCC is available on Amazon:

Hunt, M. O'N, Protus, B. M., Winters, J. P., & Parker, D. C. (Eds.). (2014). *Pediatric palliative care consultant: Guidelines for effective management of symptoms*. HospiScript Services.

I work with some of the most intelligent and caring pharmacists on our clinical team, as well as amazing hospice teams. I'm able to provide symptom management and medication support for pediatric patients across the country while also providing education and collaboration with teams. This position really brings all my passions together.

I was careful not to over specialize when I completed residency...oops, guess I did anyway. Helping minimize suffering and allowing children to live the best lives possible for the time they have left has been worth it.

Pediatric Palliative and Hospice Care Training & Educational Resources / May 2023

In-Person Training		
Education in Palliative and End-of-Life Care Program (EPEC)	https://www.bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html	<p>Education in Palliative & End-of-Life Care (EPEC) for Pediatrics is a comprehensive 24 module curriculum designed to address the needs of children, their families and pediatric oncology providers and other pediatric clinicians, with input from pediatric multidisciplinary teams and parent advocates.</p> <p>The training is taught as a hybrid of 20 distance learning modules and six in-person conference sessions. The in-person conference is offered annually.</p>
End-of-Life Nursing Education Consortium (ELNEC)	https://www.aacnursing.org/ELNEC/About/ELNEC-Curricula	<p>ELNEC Pediatric was developed by 20 pediatric palliative care experts and each year, at least three national train-the-trainer pediatric palliative care courses are offered in-person across the US. The curriculum also includes perinatal and neonatal content.</p> <p>ELNEC also offers self-paced online training courses (Core, Critical Care, Geriatric, and Pediatric) through Relias. CEs are available and learners will receive certificate of completion. NOTE: the online Relias courses are trainings, not Train-the-Trainer courses.</p>
Online Training/Educational Resources		
American Academy of Pediatrics Policy Statement: Pediatric Palliative Care and Hospice Care Commitments, Guidelines and Recommendations	https://publications.aap.org	<p>Developed by the Section on Hospice and Palliative Medicine and Committee on Hospital Care, this document outlines key guidelines and recommendations from the AAP on the delivery and other considerations in providing pediatric palliative and hospice care to children and their families.</p>
Association of Pediatric Oncology Social Workers (APOSW)	https://aposw.org/	<p>The Association of Pediatric Oncology Social Workers is a group of professionals focused on enhancing the lives of children with cancer and blood disorders and their families. They focus on how to do this through clinical social work practice, research, advocacy, education, and program development.</p> <p>Access to resources, clinical topics, etc. requires a membership login.</p>

California State University (CSU) Shirley Haynes Institute for Palliative Care	https://csupalliativecare.org/find-your-course/ (Use Pediatrics filter)	<p>This Institute offers a variety of online courses available which can be accessed anytime on a wide range of pediatric palliative care topics including communication skills, easing suffering and promoting healing, ethical principles and challenges, pediatric team support, basic pediatric care delivery, and many more.</p>
Center to Advance Pediatric Palliative Care (CAPC)	https://www.capc.org/toolkits/designing-a-pediatric-palliative-care-program/ https://www.capc.org/training-recommendations-pediatrics/ https://shop.aap.org/eqipp-talking-about-serious-illness/	<p>CAPC has developed a downloadable Pediatric Palliative Care Toolkit which addresses the unique needs of pediatric patients, and their families. It also shares out implications for pediatric program leaders.</p> <p>They have also crafted pediatric clinical training recommendations in partnership with the Pediatric Palliative Care Task Force which are appropriate for use for all clinicians caring for pediatric patients from babies to young adults, and their families. These recommendations cover core care practices like assessing the pediatric patient's (and their family's) needs/concerns; strengthening the care team/patient/family relationship and understanding care goals; pain and symptom management; and pre-planning to prevent crises.</p> <p>CAPC also collaborated with the American Academy of Pediatrics (AAP) and courageous Parents Network to create an online course, Talking about Serious Illness which is available through EQIPP on the AAP website to help facilitate open and honest conversations with parents or other family members of children living with a serious illness.</p>
Centre for Pediatric Pain Research	https://pediatric-pain.ca/for-health-professionals/	<p>While the core service of this organization is its Pediatric Pain Management Program for providers at its health centre, it does offer a downloadable book for use with children to help with pain, two videos on pain management, validated pain assessment measures, books, and professionals can be added to their mailing list, which is an international forum for informal discussion on topics related to pain in children.</p>
Coalition for Compassionate Care of California (CCCC)	https://coalitionccc.org/CCCC/CCCC/Resources/Decision-Aids-for-Healthcare-Providers.aspx	<p>CCCC offers Pediatric Decision Aids for healthcare providers which are PDF's that can be used with families to facilitate having conversations about goals of care and life-sustaining treatments for adults and children. The Decision Aids touch on discussions around breathing machines, CPR, and tube feeding, using consumer-friendly language with evidence-based information.</p>

Courageous Parents Network (CPN)	https://courageousparentsnetwork.org/	<p>CPN, while primarily a family support organization, has developed a professional portal on its website that is dedicated to the interests of physicians, advance practice providers, nurses, social workers, chaplains and allied health professionals looking to understand better what the lived experiences of these families of very sick children is like.</p> <p>These family voices share their insights in videos, podcasts, downloadable guides, and blog posts which can aid in education of professionals and families alike.</p> <p>Providers/clinicians need to register on the CPN website to gain access to these materials.</p>
International Children's Palliative Care Network (ICPCN) E-Learning Programme	https://icpcn.org/	<p>The International Children's Palliative Care Network (ICPCN) is recognized as the world leader in children's palliative care and has a wealth of educational resources and a network of members in over 140 countries.</p> <p>Educational support available through ICPCN for professionals includes: publications and resources, webinars, e-learning programming, a pain assessment app, an educational standard framework and self-audit tool, children's palliative care charters, palliative care resources, and more.</p>
National Hospice and Palliative Care Organization (NHPCO) Pediatrics	https://www.nhpc.org/pediatrics/	<p>NHPCO offers a variety of educational and training resources in its commitment to improving access to hospice and palliative care for children and their families. These include a quarterly Pediatric E-Journal for pediatric healthcare professionals, a Pediatric Concurrent Care Toolkit, a Pediatric Palliative Care Webinar Series, professional resources, and educational brochures for distribution to families (available in English and Spanish through Caringinfo.org).</p>
Pediatric Palliative Care Coalition	https://www.ppcc-pa.org/	<p>This PPC coalition provides support to both professionals and families/caregivers alike with its webinar series (see Webinar section), Firefly chats, Resource links, Lightning Bug app for families/caregivers, PPC Toolkits, and so much more.</p>
Together for Short Lives	https://www.togetherforshortlives.org.uk/	<p>A UK-based organization, Together for Short Lives supports families needing and healthcare professionals providing palliative services to children/families requiring this type of support. For professionals, they provide core care pathways, resources and best practices, and they share the latest research to help professionals offer the best care to families they can.</p>

Perinatal Hospice and Palliative Care		
Perinatal Hospice and Palliative Care	https://www.perinatalhospice.org/	This organization has featured resources for caregivers around how to care for babies and families perinatally when palliative or hospice care is required and include: conferences and training videos, professional networking opportunities, materials for use with patients, medical journal articles and other reference documents; and information on birth planning and starting a perinatal hospice and palliative care program.
Pregnancy Loss and Infant Death Alliance (PLIDA)	https://www.plida.org/	PLIDA supports healthcare professionals and patient/family advocates in their efforts to improve care for families who experience the death of a baby during pregnancy, birth, or infancy through advocacy, networking, professional continuing education, the establishment of position statements and practice guidelines, creating a network of professionals to share questions/resources/insight/support, and more. It hosts an International Perinatal Bereavement Conference and also a Perinatal Bereavement Webinar Series.
Share/Pregnancy & Infant Loss Support, Inc.	https://nationalshare.org/	Share's mission is to serve those whose lives have been touched by the tragic death of a baby through early pregnancy loss, stillbirth, or in the first few months of life. To do this they offer professional resources on their website which includes training, resource materials for use with families, educational workshops, online bereavement training, and more.
Pediatric Palliative/Hospice Care Webinars Series		
Pediatric Palliative Care Coalition	https://www.ppcc-pa.org/	PPCC (Pediatric Palliative Care Coalition), GIPCC (Greater Illinois Pediatric Palliative Care Coalition), CHPCC (Children's Hospice & Palliative Care Coalition of California), and the CSU Shirley Haynes Institute for Palliative Care have collaborated to offer a pediatric palliative care Webinar Series to raise the visibility of pediatric palliative care and to build clinicians' competencies and confidence in providing this type of care. Archived webinars are also available for purchase.
Children's Palliative Care Coalition of Michigan (CPCC)	https://www.childpalliative.org/	One of the missions of CPCC is to provide resources for medical professionals, volunteers, and families caring for children with complex and life-limiting illnesses. This is done through a yearly conference, a monthly webinar series, and national and local resources for professionals and families in palliative care, grief and bereavement, etc.

Pediatric Palliative Care Coalitions

<p>Listing of Pediatric Palliative Care Coalitions and PPC State Champions Throughout the United States</p>	<p>https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/05/PPC-Coalition-Chart_May-2021-008.pdf (Note: Chart in process of being updated)</p> <p>https://www.ppcc-pa.org/advocacy-2/statewide-ppcc-coalitions</p>	<p>These are single or multi-state coalitions that have formed to educate, advocate, conduct research, provide resources, etc. on pediatric palliative and hospice care in their specific states and/or regions.</p>
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Pediatric Educational Opportunities Provided By NHPCO

Compiled by **Amelia Emons**.

In addition to supporting the Pediatric e-Journal, the National Hospice and Palliative Care Organization (NHPCO) offers many resources and educational opportunities for pediatric palliative and hospice care. Most of our pediatric resources are available to anyone as a community service, however, a few items may require NHPCO membership to access. [Membership is available](#) for hospice and palliative care organizations and for individual practitioners who provide palliative care but are not part of a hospice, community-based palliative care provider, or other palliative care group.

Resources include the Pediatric Standards of Care, Facts & Figures (currently being revised), Concurrent Care Toolkit developed after the Affordable Care Act was enacted, among others. The National Hospice and Palliative Care Organization (NHPCO) provides pediatric educational opportunities through a variety of modes, including webinars, conference presentations, and Project ECHO. Recordings of educational opportunities are available. For more information on accessing NHPCO education, email education@nhpco.org. Below are the currently available opportunities:

[Where the Cellular Won't Roam](#) (Webinar – Recorded Oct 27, 2022)

Description: Providing pediatric palliative and hospice care in states and rural areas without established pediatric teams can be challenging. Join us for a unique learning session to review how one program's journey started within an adult hospice and developed into a statewide program. We will discuss many challenges including staffing, geography, and growth.

Learning Outcomes:

- Understand a unique pediatric care delivery model serving the child and family across the continuum
- Define unique challenges to delivering pediatric care within an adult care model
- Review approaches to support adult staff caring for pediatric patients

Faculty: Kathryn Hudson, Weston Rice

[What Adult Providers Need to Know to Care for Children](#) (Webinar – Recorded Oct 28, 2021)

Description: Adults tend to be the primary population on caseload for many hospices, while pediatric patients account for a much smaller and sometimes infrequent portion. When a pediatric patient is referred, some adult hospices need to adjust quickly to serve the unique needs of a pediatric patient and their family. Join this panel of experts from multiple disciplines as they discuss what adult providers need to know when they are referred a pediatric patient and how best to care for them and their family.

Learning Outcomes:

- The goal is to create a sense of confidence in caring for children referred to an adult program that infrequently cares for children
- To highlight some of the similarities and differences to allow planning for the occasional child referred to your program
- To encourage forming collaborative partnerships with your local center of pediatric expertise

Faculty: Josh Hauser, Kevin Madden, Meg Lawless-Crossett

Cultural Humility in Pediatric Care (Project ECHO Session –Recorded March 2, 2023)

Description: Children and Adolescents are not little adults. We often treat pediatric patients in our care as invisible patients, focusing predominantly upon the goals of their parents or guardians, and the barriers that create this inequity start with our own biases. Minors deserve the same respect and their unique needs deserve to be acknowledged.

Learning Outcomes: Project ECHO is focused on helping providers recognize opportunities for clinical or operational quality improvement in hospice or palliative care. Case-based learning presentation creates an environment for learning exchange, performance improvement possibilities, and identification of best practices.

Faculty: Christy Torkildson, Yelena Zatulovsky

Items of Interest!

Please help us keep the items of interest up-to-date. Share your news, upcoming conferences, or webinars. Are there particular podcasts that may be of interest to our readers? Send any items of interest to Christy at Christy.Torkildson@gcu.edu. Thank you.

1. Subjects and Contributors for Future Issues of this E-Journal

Our future issues will be centered on the following main themes. If you have any thoughts about these or any other topics, contributors, or future issues, please get in touch with Christy at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

Issue Topics: 2023 (Note: Subject to Change at Work Group's Discretion)

■ **Issue #72: Education & Resources for Adult Hospices Caring for Kids** What are the barriers, what is difficult to overcome in PPC; contributions due 31 May 2023.

■ **Issue #73: Pain and Symptom Management.** In reviewing the main pain/symptoms of pain, nausea/vomiting, constipation, anxiety/agitation/delirium, respiratory distress/secretions, dyspnea, autonomic dysfunction, and seizures we hope to present an interdisciplinary approach to management of these symptoms. In your practice, how can you contribute to the care of an infant, child, adolescent or young adult dealing with pain or any of these symptoms? Interested? Please contact Christy at Christy.Torkildson@gcu.edu. Or Suzanne at tocess@gmail.com or Chuck at charles_corr@comcast.net

■ **2024 – Let us know your ideas! What topics would you like to see addressed in the Pediatric e-Journal?**

2. NHPCO's Virtual Interdisciplinary Team Conference for 2023

live events have ended, However, the virtual content and on demand sessions remain available. More information on the [NHPCO conference website](#).

3. COMING SOON – NHPCO Pediatric Website Pages are being updated for easier searching!

NHPCO Palliative Care Online Resources: NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community–Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Brochures in English and Spanish for families
- Plus, more for NHPCO members

Palliative Care Programs and Professionals: Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. [Join NHPCO Today!](#)

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

4. Palliative Care Resources for Nurses, Patient Care Support Staff, and Families of Patients by Life and Death Matters, <https://lifeanddeathmatters.ca/> offers texts, workbooks, and resources for providers and family members. Although primarily focused on adults they reference across the lifespan with sound principles useful no matter the age of your patients.

The text, workbook, and companion resources support nurses and nursing students (in Canada and USA) to develop the knowledge, skills, and attitudes for integrating a palliative approach and providing excellent end-of-life care.

Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse

Textbook: 978-1-926923-11-6 **Workbook:** 978-1-926923-11-6

The text, workbook, and resources, based on national competencies, will help nurses:

- Develop best practice interactions
- Decrease fears and increase confidence and competence in caring for the dying person and family
- Develop ethically and culturally competent practices with touchstones and by relating experiences

Also available for this title: Videos, Podcasts, PowerPoint™ Presentations and NCLEX-style questions

Palliative Care Resources for Care Aids and Family

Integrating a Palliative Approach: Essentials for Personal Support Workers, 2nd Edition; 1926923162

Integrating a Palliative Approach: Essentials for Personal Support Workers 2nd Edition – Workbook; 9781926923178

This textbook is a rare text that engages you with its warmth and heart—an essential resource for all frontline caregivers and family members supporting loved ones. The companion workbook engages learners through reflective activities, crossword puzzles, worksheets and interactive projects. Video and podcast libraries available on the [Life and Death Matters website](#).

Previous Items of Interest:

5. **Did you know that the State Coalitions from Pennsylvania, Illinois, and California, with support from the Shiley Haynes Institute for Palliative Care and the HAP Foundation, host monthly, affordable webinars with continuing education units available?** [You can register](#) for one or the entire series, with discounts for multiple registrations.
6. **On that same note, did you know there was a network of state coalitions and folks interested in helping with or starting a state coalition for Pediatric Palliative Care?** For more information, **contact Betsy** betsy@ppcc-pa.org
7. **[End-of-Life Nursing Education Consortium \(ELNEC\) project](#)** has several upcoming courses.
8. **EPEC-Pediatrics will be held May 22-24;** please, email EPEC.Pediatrics@ucsf.edu for more information.
9. **Recently, the California Advocacy Network for Children with Special Health Care Needs announced their foundation had committed to increasing access to journal articles that may be difficult for family members and non-profit staff to access to improve "effective and equitable systems" as "access to scholarly work is essential to system improvement."** More information can be found on the [California Advocacy Network for Children website](#). It may be helpful to contact your state's chapter to determine what resources they may have!
10. **Courageous Parent's Network has a wealth of resources for parents, caregivers, and providers.** The list is too long to add here so please [check out their website](#).
11. **The Pediatric Palliative Care Coalition of Pennsylvania, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation have created a community resource to guide families through the funeral/memorialization planning process:**

When a Child Dies: Planning Acts of Love & Legacy

This resource is available in both English and Spanish and is FREE, thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at [When A Child Dies](#).

12. ***Pediatric Go Wish Together***: A conversation game for parents and pediatric caregivers; developed by Meghan Potthoff, Ph.D., APRN-NP, PPCNP-BC, CPNP-AC in collaboration with Coda Alliance. This game is “developed to help parents navigate the unimaginable journey of their child’s illness.” “It is a tool that provides parents and providers a way to think and talk about what’s most important to the child”. More information can be found at [Pediatric Go Wish Together](#)
13. **Have you heard of the new organization PallCHASE: Palliative Care in Humanitarian Aid Situations and Emergencies?** Their primary ambition is the relief of suffering, and their purpose “To work in partnership through a visible and effective network to advocate for palliative care integration in humanitarian situations or emergencies...”. Please visit their website for more information, healthcare professional training and resources in a variety of languages! [Click HERE](#) to check out their website!
14. **Another great new group is the Child Life in Hospice and Palliative Care Network, which provides child life specialists working in hospice or palliative care access to resources, education, research, and networking opportunities to establish and provide best practice care for patients and families experiencing a serious illness.** They are requesting that interested members fill out a brief survey, sign up today at [CLHPN](#)
15. **A Toolkit of Autism, Grief, and Loss Resources by Hospice Foundation of America**
The [toolkit](#) will include a variety of materials and resources, such as:
- suggestions for responding to the grief experiences of autistic adults;
 - ways to provide for choice and inclusion in rituals;
 - tips for communicating the news of death;
 - social stories on grief for adults;
 - videos about grief, including interview clips with autistic adults and their families;
 - two complimentary continuing education (CE) programs for professionals; and much more!
16. **A resource for pregnancy or infant loss is [Share: Pregnancy & Infant Loss Support](#).** Share was started in 1977 in response to the urging of one bereaved family by Sr. Jean Marie Lamb, OSF. Initially providing support groups, they now offer online support groups, education, and support for families and caregivers.
17. **NHPCO Palliative Care Online Resources:** NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:
- Community-Based Palliative Care
 - Legal and Regulatory Resources
 - Webinars and Courses
 - Plus, more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world’s largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. Join NHPCO Today!

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

18. **The Pediatric Palliative Care Coalition of Pennsylvania (PPCC) has made a new resource available – a Sibling Grief and Bereavement Toolkit.** This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities. Please see the associated article in this edition! Below is a link to the toolkit and one of the activities – “**Make a Feelings Chart**”. [View the PPCC Sibling Grief and Bereavement Toolkit.](#)

Toolkit Activity

For children who are grieving the loss of their siblings, returning to school can be a difficult transition. Check out this month's highlighted activity from the toolkit that may help children and teens in the upcoming school year.



Make a Feelings Chart by [downloading the activity](#). PPCC invites you to share this information with parents, caregivers, medical professionals, providers, therapists, etc.

19. Pediatric Hospice and Palliative Care Resources:

■ **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org

NHPCO's Palliative Care Resource Series includes pediatric palliative resources like:

- Communication Between Parents and Health Care Professionals Enhances
- Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy
- Consideration for Complex Pediatric Palliative Care Discharges
- Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care
- Nonpharmacological Pain Management for Children
- Sibling Grief
- Pediatric Pain Management Strategies
- Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations
- In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled *Determination of Hospice Medication Coverage in CHILDREN*.

20. Trends in Pediatric Palliative Care Research

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit their blog, browse in their library, or join the Zotero group. View the New Citation List in their library.

Please note the archived issues are available as a community-service by NHPCO and can be found at www.nhpco.org/pediatrics or by reaching out to Pediatrics@nhpco.org.



NHPCO

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