

# ChiPPS E-Journal

Issue 50 | February 2018

***Celebrating the Past and the Future of Pediatric Palliative/Hospice Care, ChiPPS, and the ChiPPS E-Journal***

**50<sup>th</sup>**  
**ISSUE**

***Children's Project on Palliative/Hospice Services***  
Released in collaboration with the National Hospice and Palliative Care Organization

National Hospice and Palliative Care  
Organization



**Produced by the ChiPPS  
E-Journal Work Group**

**Charles A. Corr, PhD**, Member, Board of Directors, Suncoast Hospice Institute, Pinellas County, FL; Senior Editor

**Kathy Davis, PhD, MSED**, Director, Pediatric Education and Palliative Care, Department of Pediatrics, University of Kansas Medical Center, Kansas City, KS

**Ann Fitzsimons, BS, MBA**, Executive Director, here4U, Inc., Farmington Hills, MI; Co-Chair

**Betsy Hawley, MA**, Executive Director, Pediatric Palliative Care Coalition, Pittsburgh, PA

**Melissa Hunt, PharmD**, Pediatric Clinical Pharmacist, HospiScript, an Optum Company, Montgomery, AL

**Nathan Ionascu, MD**, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY

**Kelly Cronin Komatz, MD, MPH, FAAP, FAAHPM**, Clinical Medical Director, Community PedsCare Program, Medical Director, Pain and Palliative Care, Wolfson Children's Hospital and Wolfson Center for the Medically Complex Child at University of Florida, Jacksonville, FL

**Rachel Levi, PhD**, Licensed Psychologist, Private Practice, Oakland, CA

**Suzanne Toce, MD**, Retired Neonatologist, Gundersen Lutheran Health System, La Crosse, WI

**Christy Torkildson, RN, PHN, PhD**, FPCN, Director, UCSF Benioff Children's Hospital Oakland Pain and Palliative Care Program; Co-Chair

**ISSUE TOPIC**

**Celebrating the Past and the Future of Pediatric Palliative/Hospice Care, ChiPPS, and the ChiPPS E-Journal**

Welcome to the 50th issue of the ChiPPS E-Journal. We are pleased and gratified to reach #50 in this series. That has only been possible with the support of NHPCO, the Advisory Council of ChiPPS, the ChiPPS E-Journal Workgroup, and hundreds of contributors over the past 13 years. Thanks to everyone who has helped us reach a total of 50 issues thus far (and 50 more to come???)

This issue of our E-Journal offers an expanded collection of articles by contributors who responded to our invitations to them either: (1) to look back on the development of pediatric palliative/hospice care and of ChiPPS and its E-Journal; or (2) to look forward to their hopes and predictions for the future of our field. Not every busy person whom we invited was able to accept our invitations, but those who did were left free to write as they wished. We believe the results that appear in this enlarged issue constitute a rich trove of experiences and insights that will benefit any reader with an interest in our field.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by ChiPPS E-Journal Workgroup, co-chaired by Christy Torkildson and Ann Fitzsimons. Archived issues of this publication are available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Our tentative plan for the remainder of 2018 is to develop issues on Hospice & Bereavement Support in Crisis Situations, Caring for Diverse Families/Populations, and A Legislative Update. If you have any thoughts about these topics, contributors, or future issues, please contact Christy at [christytork@gmail.com](mailto:christytork@gmail.com) or Ann at [ann@here4U.net](mailto:ann@here4U.net).

*Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.*

# CONTENTS

## **My Apology**

p. 5

**Scott Newport**

In this article, our resident poet, essayist, and father of a child who died of heart disease at a young age, reports on his participation in an orientation for first-year medical students at the University of Michigan Medical School. One of the medical students asked, “What is the first thing we, as med students, should be doing?” Scott answered that question this way: “The first thing you should learn to practice is the art of listening.” This article tells the story of that meeting and of the small group discussion that followed. Because it reminds us of the great importance of ACTIVE LISTENING in pediatric palliative/hospice care, this article and its central advice seems to us to deserve a place as the keynote contribution to this issue.

## **Pediatric Palliative Care through the Lens of CHIPPS: Origins and Evolution**

p. 7

**Marcia Levetown, MD, MMM, FAAP, FAAHPM**

This article reflects on author’s efforts in the early 1990s to improve care for children living with life-threatening conditions by bringing together the work of disparate pioneers “with the goal of enabling enthusiastic start-up programs to effectively provide comprehensive care for” such children. These efforts and some grant funding led to the formation of a multinational leadership group that eventually became the Children’s International Project on Hospice and Palliative Services (then called ChiPPS) and that arranged “an in-person meeting of 30 international pediatric palliative care experts and advocates that took place in 1998 in Galveston, Texas.” Some of the project’s early activities are then described.

## **Reflections on the Evolution of Palliative Care for Children**

p. 8

**Betty Davies, RN, PhD**

Dr. Davies begins with her early assignments to care for dying children “as a nursing student and new graduate, without any formal instruction and minimal support about how to deal with death, dying and bereavement.” From those initial contacts, she offers a sweeping account of the development of palliative care for children through the 1970s, 1980s, 1990s, and 2000s. To this, she adds an overview of research development and what she regards as five remaining challenges for the field. Her conclusion: “I believe that the development of ChiPPS has played an integral role in the ongoing evolution of PPC, particularly in the US.”

## **Reflections on the Growth and Development of Children’s Palliative Care**

p. 15

**Stephen R. Connor, PhDAs**

Former vice president for research and development at NHPCO (then NHO), Dr. Connor helped plan and implement the 1998 conclave that became ChiPPS. Here he describes early publications from that project. Now, as Executive Director of the Worldwide Hospice Palliative Care Alliance, he reviews recently-published estimates of the global need for children’s palliative care and provides a map of the global ability to provide that care. His conclusion is that “ChiPPS has made major contributions to the field of pediatric palliative care including many influential publications and an exceptional continuing newsletter on key issues in the field. While there is still a long road ahead the early pioneering work of ChiPPS set the stage for many advancements in the field and continues to be a source of inspiration in the USA and globally.”

## **Reflections on CHIPPS: Celebrating a Road Well-Travelled and Opening Up to New Challenges**

p. 19

**Danai Papadatou, PhD**

Dr. Papadatou reviews in this article some of her activities in our field prior to and following the 1998 CHIPPS conclave. On that basis, she offers six “challenges ahead that require our relenting perseverance and collective coordination.”

## **Reflections on ChiPPS: From Then to Now**

p. 22

**Stacy F. Orloff, Ed.D., LCSW, ACHP-SW**

After reviewing achievements during the first 10 years when she was most closely involved with ChiPPS, Dr. Orloff adds that she is “most proud of how different the field of pediatric hospice and palliative care looks from the initial ChiPPS conclave in 1998.”

**Musings on the Evolution of CHIPPS and the E-Journal**

**p. 23**

**Suzanne S. Toce, MD**

Beginning her involvement in this field in the mid-1990s, Dr. Toce describes the state of the field at that time. She reports that an Excellence in End of Life Care grant from the Robert Wood Johnson Foundation led her to involvement in what became ChiPPS and her long-time participation in the ChiPPS E-Journal Workgroup. She concludes by noting that: “We have come a long way, but we are not ‘there yet’” and outlines a series of indicators that might tell us that we have achieved what we have hoped for in our field.

**ChiPPS – Celebrating 50 E-Journals**

**p. 26**

**Marcia Lattanzi Licht, LHD, RN, LPC**

This article reiterates that, with the support of NHPCO and under the leadership of Galen Miller, “A small group of well-respected pediatric palliative and hospice care professionals pulled together to create ChiPPS, a national collaborative for pediatric palliative and hospice care.” The author maintains that “Three elements became central to ChiPPS from the outset, and also parallel the origins of the hospice movement”: a significant level of **Passion**, the commitment to **Networking**, and the concept of **Paying It Forward**. Dr. Lattanzi Licht expresses “Congratulations and great appreciation to all involved in making the ChiPPS E-Journal such a living representation of all that is part of Pediatric Palliative and Hospice Care.”

**The ChiPPS E-Journal**

**p. 27**

**Charles A. Corr, PhD**

Dr. Corr offers a brief history of ChiPPS and the ChiPPS conclave, followed by an account of the first and second series of the ChiPPS E-Newsletter, which became the ChiPPS E-Journal in February, 2014. He adds a list of all previously published issues with dates and subjects, and invites interested parties “to join in this collaborative effort ... [to] help define the future of this ongoing service and enrich what it has to offer to the community of professionals, volunteers, and family members who are involved in pediatric palliative and hospice care.”

**A Personal Perspective of Palliative Care for Children from the UK**

**p. 31**

**Ann Goldman, MA, MB, BChir, FRCPCH**

Dr. Goldman describes her participation in “the first multidisciplinary, hospital-based children’s palliative care team.” This led to her participation in “an important initiative ... to establish an umbrella organisation to work on behalf of the needs of all children with life-limiting and life-threatening illnesses. This was ACT (the Association for the Care of Children with Life Limiting and Life Threatening Illnesses), now called Together for Short Lives, which has had a powerful role in lobbying to raise the profile and improve the care for the children and families and support and educate clinicians, throughout the UK.” Her conclusion: “I believe that one of our most important roles for the future is for palliative care for children to be recognized as a beacon of good clinical practice and humane care. We have a powerful opportunity to use and teach the ethos and principles of palliative care and through this we can help improve care for children and families around the world.”

**Advance Planning in Pediatric Care**

**p. 33**

**Blyth Lord, EdM**

Here the Executive Director of the Courageous Parents Network draws on a survey of parents who had used their services and other evidence to argue that “the good news, the really good news from where I sit as a parent advocate for pediatric palliative care, is that the articulated need as seen in our data corroborates the sense that growing awareness of and demand for advance care planning can move palliative care services into prime time—out of the small circle of specialists and into the larger circle of primary care and front-line providers who work with seriously-ill children.”

## **Education: The Key to Providing, Maintaining, and Sustaining Excellent Pediatric Palliative Care**

p. 35

***Pam Malloy, MN, RN, FPCN, FAAN, Cheryl Thaxton, MN, RN, CPNP, FNP-BC, CHPPN, Vanessa Battista, RN, MS, CPNP, and Betty Ferrell, PhD, RN, MA, CHPN, FPCN, FAAN***

This article focuses on the ongoing need for education for nurses who care for children with life-threatening or chronic illnesses and their family members. The authors trace the development of the ELNEC-PPC (End-of-Life Nursing Education Consortium—Pediatric Palliative Care) project and provides examples of how that education can and has been implemented in practice.

## **The Future of Pediatric Hospice and Palliative Care**

p. 39

***Rachel Thienprayoon, MD, MSCS, FAAP, FAAHPM***

Dr. Thienprayoon notes the recent rapid growth in the availability of dedicated pediatric palliative medicine fellowship programs, the fact that “diseases that were once uniformly fatal are being transformed into chronic illnesses of childhood and young adulthood,” and other changes which mean that while general pediatricians and other subspecialists can now become capable of providing basic, primary palliative care, “subspecialty-trained pediatric hospice and palliative care providers will thus be unencumbered to focus on secondary and tertiary palliative care needs: management of refractory symptoms, navigating difficult discussions about goals of care, and assisting with complex medical decision making.” Along with developments in perinatal palliative and hospice care, she observes that “over the coming years it will be critical that research and quality improvement efforts not only grow, but remain tightly wed, bearing fruit in the form of measurable, evidence-based outcomes and benchmarks across programs and settings.”

## **Advancing the Future Growth of Pediatric Hospice and Palliative Care**

p. 40

***Conrad Williams MD, FAAP, FAAHPM***

Dr. Williams writes: “As our field looks to mature, it is imperative that we focus our efforts in the coming years on strengthening the specialty through dedicated and collaborative work on enhancing the clinical, advocacy, research, and educational efforts with the goal of increasing access to palliative care services across the country and beyond.” His article describes a program for achieving these enhancements.

## **Early Integration of Pediatric Palliative Care into Pediatric Oncology Practice: The Time Is Now**

p. 42

***Holly Spraker-Perlman, MD, MS, Angela Snyder, DNP, and Justin N. Baker, MD***

The authors of this article maintain that “By getting PPC teams involved in the care of patients EARLY, relationship building and trust can begin near diagnosis and continue throughout the child’s treatment trajectory regardless of outcome. The stigma that receipt of palliative care services is equivalent to ‘giving up’ will be removed as PPC teams are incorporated earlier into the care of any patients with quality of life needs regardless of the outcome of therapy.” They argue that pediatric palliative care should even be integrated into the care of patients who may be cured of their disease because “most children with cancer SUFFER” and “The goal of PPC intervention is to reduce suffering.” To implement early integration of PPC into pediatric oncology practice, these authors describe a model that “depicts PPC integration at three levels”: 1) at the consult level where PPC providers connect with patients and families when notified by primary oncology teams, 2) with trigger criteria to capture “higher risk” patients and families automatically, and 3) at an institutional level with PPC education and policy.”

## **Positioning Pediatric Palliative Care in Prime Time: Progress Highlights**

p. 45

***Rebecca A. Kirch, JD***

Writing as Executive Vice President for Healthcare Quality and Value of the National Patient Advocate Foundation, Dr. Kirch offers several “prominent examples where PPC is already positioned to further the field’s progress.” These examples include: the Pediatric Palliative Care Research Network; the National Palliative Care Registry; a project involving Mapping Community Palliative Care; The National Consensus Project; and the policy pursuits of the Roundtable on Quality Care for People with Serious Illness. She concludes: “These initiatives illustrate how effective advocacy through a variety of PPC leadership steps is accelerating progress in the field.”

**Statewide Pediatric Palliative Care Coalitions**

**p. 48**

*Devon Dabbs, Kate Detwiler, Betsy Hawley, and Kristin James*

This article describes the role of statewide or regional pediatric palliative care coalitions in advancing PPC care, uses concrete examples to show what such coalitions are currently doing, and provides a chart listing existing coalitions by name, state, contact person, and website (where available).

**Future Visions for Pediatric Palliative Care**

**p. 50**

*Brian Carter, MD*

Drawing on historical antecedents and a graph of PPC entries in PubMed over the past 50 years, Dr. Carter outlines and explains three major considerations in the field in the next decade: (1) "I believe that pediatric palliative care (PPC) clinicians will need to acquire a working facility with the new genetics, genomics, and individualized pharmacogenomics"; (2) "A second area of future import for PPC clinicians will be the continued momentum for the field to advocate that PPC services be initiated concurrently with intensive care, oncologic care, and the treatment of chronic and complex pediatric health care conditions"; (3) "PPC clinicians need to advance not only qualitative work and the development of best practice models, but also conduct research that will advance the field." He concludes: "The past informs the present and lays the groundwork for what I believe to be a bright, yet challenging, future for PPC. It will require continued hard work, insightful young leaders, and energized parents, clinicians, and policymakers working together in advocacy and legislative channels to ensure the place of the specialty within the breadth of essential benefits for children in North America."

**10 Interesting Research Questions in Pediatric Palliative Care**

**p. 53**

*Harold (Hal) Siden, MD, MHSc, FRCPC*

Drawing on the monthly citation list, "Trends in Pediatric Palliative Care Research," Dr. Siden notes the rapid growth in research publications in PPC and the striking difference in the nature of these articles over the past 20 years. He then organizes extensive lists of citations (126 in all) according to 10 interesting research questions that he would like to see addressed.

**A Message from the ChiPPS Co-Chairs**

**p. 64**

*Holly Davis, MS, APRN, and Marilyn A. Fisher, M.D., M.S.*

This article applauds the work of the ChiPPS E-Journal, takes note of the many other learning opportunities provided by the ChiPPS Advisory Council through its multidisciplinary collaboration, and thanks all who have made this education and support for pediatric palliative and hospice care available over many years.

**Thank You for Many Significant Contributions**

**p. 65**

*Edo Banach, JD*

The President and CEO of NHPKO expresses his appreciation to all who have made possible 50 issues of the ChiPPS E-Journal and acknowledges many of the key accomplishments of ChiPPS since 1998. Nevertheless, he acknowledges the ongoing existence of barriers to pediatric palliative and hospice services, and calls for collaboration among all who are working to increase access to such services on behalf of children with life-threatening and life-limiting conditions and their family members.

**Items of Interest**

**p. 68**

## MY APOLOGY

*Scott Newport*

Evan's father

[ScottandPenni@hotmail.com](mailto:ScottandPenni@hotmail.com)

It was the fourth day of orientation for first-year medical students at the University of Michigan Medical School, and even though I wasn't a student, I couldn't keep myself from speaking up that day. There were about 200 students in the jammed auditorium, accompanied by professors, doctors, and my group of about twenty Patient and Family Centered Care (PFCC) staff and volunteers. This session was called, ICE: Initial Clinical Experience.

"What are we missing here?" a young med student asked, addressing the patient panel on stage. "I know we are supposed to be asking you experts about your patient experience, but what question, from your view, should we really be asking?"

One by one each of the three panelists gave quite nice answers. Sitting in the last row of the warm auditorium, I started to fidget and finally got the courage to raise my hand.

After a couple of other med students were acknowledged by the facilitator to ask their questions, my hand was graciously recognized.

"Scott, did you have something to add?" Molly, the director of PFCC said.

"Yes, I wanted to go back to the one question about what are we missing, what should we be asking as med students."

I looked over toward the student who had asked the question and said, "I think the most important question is, 'What is the first thing we, as med students, should be doing?' I would answer your question this way: The first thing you should learn to practice is the art of listening."

Soon after I said that, I wondered if my comment was out of place, if I would need to apologize to Molly for overstepping my place as a PFCC member in this med school class at the dismissal of the meeting. I mean, only the students were invited to ask questions.

Before I could ponder on that anymore, the plenary was over and it was time for me to lead a small discussion group of med students to reflect on the previous session.

I took a deep breath as I entered the small classroom, and found an empty seat at the far end of the long conference-style table.

I immediately introduced myself as a parent of a child who had died of heart disease at a young age and listed my current work as an advocate and freelance writer, while earning a living as a carpenter.

"Can we go around the room and tell us your name, why you went into medicine, and what are your expectations for today's discussion," I began.

About 90% of the med students had had a medical experience as either a child of a physician or told an impactful story about a family member who had a medical crisis.

"I remember when doctors would come to our home to see my grandma who was dying and these doctors really broke it down for us," one student said. "I want to be able to do that for a family one day. I admired them."

I then shifted the conversation to the Cleveland Clinic empathy video we watched in the large group session.

The video started out with a quote by Henry David Thoreau: "Could a greater miracle take place than for us to look through each other's eyes for an instant?" It then ended with this thought: "If only you could feel, see or hear what others are

experiences, would you treat them differently?"

"After seeing the video," one student said, "I thought about the folks on the patient panel and how we never know what is going on with a person. I mean, I would never have guessed the serious issues those guys had by just looking at them."

As we continued to talk, I told them many of my own personal stories of our family's journey with Evan as well as the many families of terminally ill kids that I have personally mentored.

This was my fourth year of ICE and these students were awesome, one of the most engaging groups I have worked with. I can usually tell which students will champion the Michigan Medicine difference of excelling in Patient and Family Centered Care.

One of the stories that particularly struck me was a student who talked about at his last job at a coffee shop. He could make the perfect caffeinated cocktail in record time. But one day he decided to look someone in the eye and ask, "So what's new in your life?"

That day, he learned the importance of human connection. He learned he could still make the drinks fast, but the smiles from the customers were the real pay-off for him. I cheered inside as he continued to talk, the whole group nodding their heads at his epiphany.

As he finished, I talked about how important it is to first make connection before we start providing medical information to patients. Until we make connection, we will never be able to have meaningful discussion and build trust.

"I remember when I walked into a room to see a dad of a dying child," I stated. "I had been informed his wife had died from a drug overdose five weeks earlier."

As I walked up to him in that pediatric intensive care unit, he said, "What's up with your hands?"

His first words tripped me up for a minute but then I said, "I'm a carpenter."

"I work with my hands, too," he replied. And just like that, we made a connection.

Before I could go any further I asked the group, "What time are we supposed to be done?"

To my total embarrassment they answered, "Twenty minutes ago."

Immediately the whole class giggled and my face became hot like I did when I was scolded as a kid. The only thing I could do then was to beg for forgiveness.

But in the middle of my repeated apologies, the former coffee-shop-guy looked straight at me and said, "Scott, did you see one of us look back at the clock on the wall?" He was right—everyone was engaged in our discussion.

Then, to my surprise, before we stood up, everyone applauded.

On my way home, I reflected on the day's events and my suggestions to these new med students at the opening meeting.

"Today is the day to start becoming a doctor and the first thing you should learn to practice is the art of listening."

I'm glad I spoke up, and even more glad that I share my experiences with these students to help them become the best doctors they can be in the future. My stories and experiences are valuable, and I realized that I don't ever need to apologize for that.

**Editor's Note:** Scott appears briefly, along with many other family members and professional health care providers, in a video (<https://youtu.be/9e07OjnYYJM>) describing a project at C. S. Mott's Children's Hospital at the University of Michigan that seeks to help staff and faculty with end-of-life issues in pediatrics.

## PEDIATRIC PALLIATIVE CARE THROUGH THE LENS OF CHIPPS: ORIGINS AND EVOLUTION

**Marcia Levetown, MD, MMM, FAAP, FAAHPM**

**Independent Consultant and Educator**

[Dr.levetown@gmail.com](mailto:Dr.levetown@gmail.com)

In 1993, when the internet and email were only beginning to be used by non-military personnel, I had taken my first job out of a pediatric critical care fellowship and desperately sought information about how to better care for children living with life-threatening conditions (CLWLTC); the ICU did not seem to be the right place for these kids and there were no programs to provide continuity of care and family support once they left the hospital. The local hospice, the only one in the area, had cared for a total of 8 children in its 11-year history, but was very willing to learn more. The 6-month restriction was a fearsome barrier, as was the need to acknowledge a terminal prognosis.

With the help of an academic research librarian, I was able to find a threadbare patchwork of practice and knowledge of alternative approaches to the care of CLWLTC and their families, championed by pioneers such as Charles Corr, Belinda Martin, Kate Faulkner, Ann Goldman, Cindy Simpson Byrne, Betty Davies, John Collins, Myra Bluebond-Langner, Ann Armstrong Dailey, and a few others. Given their different disciplines, countries of origin, and practices, each had evolved specialized niche knowledge and skills. With the goal of enabling enthusiastic start-up programs to effectively provide comprehensive care for CLWLTC, there was a need to coalesce existing knowledge into a compendium for all to access. It might also propel the field rapidly if there were an evidence base developed by a worldwide consortium through robust research related to various issues relevant to pediatric palliative care.

To pursue these goals, a core, multinational leadership group was formed: Stephen Liben, Kate Faulkner, Betty Davies, Ann Goldman, and I collaborated to identify healthcare professionals around the world who might have an interest in participating in such an effort. Grant funding was obtained from Roxane, Purdue Pharma, the Project on Death in America, and the Arthur Vining Davis Foundation; the Children's International Project on Hospice and Palliative Services (ChiPPS) was born!

Kate had a long track record with the NHO, as it was known then, and approached them to facilitate our efforts. NHO was extremely generous in its support and assigned Stephen Connor, the Vice President for Research, as our point person. Together, we organized an in-person meeting of 30 international pediatric palliative care experts and advocates that took place in 1998 in Galveston, Texas. Innovators such as Tomasz Dangel from Poland, Michael Collins from Australia, Danai Papadatou from Greece, and others enriched our mutual knowledge and understanding.

The meeting was facilitated by Marcia Lattanzi-Licht, a highly respected and multi-talented expert in grief and loss, as well as in organizational development. After introductions and orientation, we identified priorities and divided into 5 groups, each tasked with a chosen topic to parse out and pursue. It was a privilege to be a member of the Administrative and Policy group, and to work with visionaries including Sue Huff, Stacy Orloff, Brian Carter, and many others to create a blueprint, "A Call for Change," published in 2001, that contributed to the concurrent care benefit (non-restrictive Medicaid Hospice benefit for children), emulated by many private payer sources. This legislation has resulted in the provision of palliative care services to thousands of children who likely would not have had access otherwise.

Most members of the larger group contributed to the *Compendium of Pediatric Palliative Care*, a hard copy compilation of brochures, wisdom, protocols, promotional material, and the like, in an attempt to jump start new programs and help existing programs succeed more quickly to serve more children. The notebook was sent to each of the existing 696 U.S. hospices and grant monies were obtained from the Robert Wood Johnson Foundation to send 350 additional copies to healthcare providers in other nations.

Over time, ChiPPS became ChiPPS, the Children's Project on Palliative and Hospice Services, with the majority of continuing leadership members being based in the U.S. As research began to slowly take off at universities and hospices around the world, the ideal of a research collaborative has taken place independently and under the leadership of Joanne Wolfe, Christy Ullrich, Sarah Friebert, Chris Feudtner, Barbara Jones, Betty Ferrell, and others.

No longer is a 3-inch binder of hard copy information needed to promote knowledge and practice in pediatric hospice and palliative care. Now, with the push of a few buttons, everything is available wherever you are. Pub Med, Research Gate, and even Google and the like have brought us together electronically and made information so much easier to find! Whereas 154 total articles were listed in Pub Med with a key word of pediatric palliative care in 1996 when we started, more than 250 per year have been published for each of the last four years. Nurses and physicians can be board certified in pediatric palliative care. The American Academy of Pediatrics has a Section of Hospice and Palliative Medicine as well as policies devoted to pediatric palliative care, and it hosts an open and active listserv, available to professionals of all disciplines as well as patients and family members. Many children have benefitted from the generosity of practitioners who respond immediately to clinical questions and from the insights of family members. We have even risen to the top of leadership at palliative care organizations. The 2018 President of the American Academy of Hospice and Palliative Medicine is a pediatrician (congratulations to Joanne Wolfe)!

For its part, ChiPPS provides a treasure trove of information and advocacy, including the online *Education and Training Curriculum for Pediatric Palliative Care*, a primer on the ins and outs of the concurrent care hospice benefit (thanks to Sarah Frieber's leadership), the promulgation of the 2009 standards for pediatric hospice care, statistics about pediatric hospice care programs and usage, and quarterly in-depth reviews and perspectives on topics relevant to practitioners and recipients of pediatric palliative care. These are crucial resources with practical import and immediate applicability. Huge thanks to Chuck Corr for his dedication in editing and producing the quarterly review for these many years!

In 1994, when I chose to dedicate my full professional attention to pediatric palliative care, my Chairman told me he could not support me, even part time. For two years, I worked with no salary out of my car. Even funding from the PDIA Faculty Scholar Program for three years did not change his mind, and I migrated to the Internal Medicine Department, splitting my time between adult and pediatric patients and education. My subsequent opportunities remained in the adult world, changing my focus away from my original training and passion; I am proud of the contributions I was nevertheless able to make over the years that honored the original goals of the ChiPPS initiative. Today, in contrast, there are numerous pediatric palliative care departments and fellowships and they are expanding their ranks. There are handbooks and textbooks of pediatric palliative care and palliative nursing to guide all who wish to learn more, even outside of these formal training programs.

While the evolution of Pediatric Palliative Care has felt challenging and slow at times, looking back, we have come so far! I hope that NHPCO will encourage its members to provide care to CLWLTC, so that the excellent care provided in the hospital can be continued in the child's home and community. I hope too that we, as a field, will advocate for telehealth solutions so that children in rural and international locations can benefit from the progress in pediatric palliative care knowledge and practice. With the tools that ChiPPS has created and progress coming from all corners, there is now every reason to hope that, in the foreseeable future, each child living with a life-threatening condition will have access to compassionate, patient and family-centered care throughout the illness trajectory.

## REFLECTIONS ON THE EVOLUTION OF PALLIATIVE CARE FOR CHILDREN

**Betty Davies, RN, PhD**

**Adjunct Professor, School of Nursing, University of Victoria and Professor Emerita, Family Health Care Nursing, University of California San Francisco**

[daviesb@uvic.ca](mailto:daviesb@uvic.ca)

I clearly remember the excitement of meeting in 1998 with 35 pediatric palliative care individuals from around the world. We gathered together to share thoughts, ideas, challenges, and hopes for the ongoing development of pediatric palliative care (PPC) – and ChiPPS was the result. It is with great joy and satisfaction that I reflect back on those early days and the various projects that were borne out of that meeting - including the fledgling flight of the simple newsletter that has become the ChiPPS e-journal! My reflections also trigger even earlier memories:

I remember that as a nursing student and new graduate, without any formal instruction and minimal support about how to deal with death, dying and bereavement, I cared for many dying children. Susie, age four, had leukemia. Her favorite stuffed toy was a small green frog with red spots. As I bathed Susie's little body, the characteristic bruises and red spots of leukemia were evident. Holding up "Froggy" with both hands and pointing to his spots, she said matter-of-factly, "Froggy has spots because his blood is sick, very sick. He has more spots every day. His spots will never go away." I continued to gently dry her, responding only a quiet "Umhum." She sighed, and affirmed, "I have spots just like Froggy's." I was in awe of Susie's simple but accurate description; this child knew more about her condition and her prognosis than anyone realized. Back then, death was not a topic of conversation between physicians and patients, nor between patients and their families and especially not in pediatrics. Looking back, I realize that ChiPPS came into being within the context of PPC's evolution over recent decades.

The earliest work in the field that has come to be known as *pediatric palliative care* centered on the care of children like Susie, children with leukemia who were dying. Acute lymphocytic leukemia, discovered in the early 1960s, and other childhood cancers took over from infections, measles, whooping cough, and unidentifiable illnesses as the most frequent cause of death by disease in children. Then, development of chemotherapy and radiation therapies meant that death from leukemia and many other cancers was no longer inevitable. When I cared for Susie, most children with leukemia died; now 90% of children with acute lymphoblastic leukemia survive.

### **The 1970s and 1980s**

The focus turned to how children like Susie and their families coped (e.g., Binger et al., 1969) and how health care professionals might help these families (e.g., Ablin et al., 1971). There was also a growing interest in the psychosocial realm of experience and the effects of early childhood experiences. Researchers interested in studying children and death turned to Piaget's theory of cognitive development as a framework that concluded healthy children did not develop a mature concept of death until after the age of nine years. Thus, professionals working with children with cancer or any life-threatening illness assumed that ill children under ten years of age were unaware of their diagnosis or prognosis and had little or no anxiety about their bodies or future. They reasoned that if adults did not discuss the seriousness of their illness with them, the children would not experience anxiety. But my experience with Susie and other children like her taught me that this was not the case. Studies by Waechter (1971), Spinetta (1973) and Bluebond-Langner (1978) made a strong case for children's awareness of their own illness and dying, and argued for parents and health care professionals to not care for them in silence.

Another significant development focused on the location of care for children with cancer and subsequently other life-threatening conditions (LTC). I cared for Susie and other children like her on general pediatric units; only in 1975 were the first specialty units for children with cancer created. Then, Martinson's ground-breaking work demonstrated that a child's care could be provided as effectively by parents and nurses at home, thus introducing the option of home care for families who desired it (Moldow & Martinson, 1980; Martinson et al., 1986). Subsequent studies reported on improved outcomes for the siblings and parents of home care compared to hospital care for children with cancer (Lauer et al., 1983; Lauer et al., 1985).

In 1985, Ann Goldman at Great Ormond Street Hospital in London, developed the first program to follow children dying from malignant diseases in hospital oncology units. She and two clinical nurse specialists were involved with children from diagnosis and throughout the disease trajectory to manage symptoms and to work with local care providers to facilitate home care and hospital care as needed. In Canada, the first hospital-based pediatric palliative care program was in the Toronto Hospital of Sick Children in 1986, the second at Montreal Children's Hospital.

Children's hospices created another venue of care for children with cancer and with LTC and their families. Premature babies of younger and younger gestational age were surviving longer with LTC due to technological innovations in neonatology. In 1982, Sister Frances Dominica, a nurse and Anglican Sister, created Helen House in Oxford, England, the world's first free-standing hospice. Her mission was to provide respite as well as end-of-life care and bereavement follow-up for families of children with LTC (Burne, Dominica, & Baum, 1984).

Four other events during the 1980s were of significance to the development of PPC. First, in the US in 1983, Ann Armstrong-Dailey created Children's Hospice International (CHI), a non-profit organization with the objective of providing education, legislation, and support for families of children with terminal illness (<http://www.chionline.org/>). Second, Charles and Donna Corr edited a book, *Hospice Approaches to Pediatric Care* (1985), with the goal of bringing together those within the hospice movement and members of the pediatric health care community so they could learn from each other. Third, in 1989, the first International Conference on Children and Death, was hosted in Athens, Greece by Dr. Danai Papadatou, a clinical psychologist, and her pediatrician father, Professor Costas Papadatos. This conference, the first to bring together practitioners, educators, and researchers to converse about their work, resulted in a compilation of their cross-discipline endeavors (Papadatou & Papadatos, 1991).

The fourth development pertained to grief and bereavement, an integral aspect of PPC. Well aware of the impact of a child's death on parents and siblings and the lack of attention to children's grief, a pediatric oncology nurse, Beverly Chappell, founded the Dougy Center for Grieving Children in Portland, Oregon in 1982 (Chappell, 2007). This program was the first of its kind and has served as the model for over 165 other such programs throughout North America, Asia, and other areas of the world. As well, the neophyte field of neonatal palliative care began to attend to the bereavement needs of families. In 1981, Rana Limbo, a nurse working with Bereavement Services in the [Gundersen Health System](#) located in La Crosse, Wisconsin, developed a comprehensive approach to caring for families whose babies died during pregnancy or shortly after birth. The program known as Resolve Through Sharing (RTS), was unique in healthcare at the time and is now known and used worldwide (<http://www.bereavementservices.org/resolve-through-sharing>).

### The 1990s

The 1990s saw substantial growth in PPC. In 1991, the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), now known as Together for Short Lives, was formed in the UK. ACT was the first such organization to focus on working to achieve better quality of life and care for all life-limited children and their families, accomplished in part by the publication of numerous resource documents, such as three editions of *A Guide to the Development of Children's Palliative Care Services* (2009). In 1993, the first *Oxford Textbook for Palliative Medicine* (OTPM) included an edited section on PPC (Davies, 1993), affirming that PPC was indeed a legitimate field of study related to, but different from, adult palliative care. The OTPM included this PPC section until the first *Oxford Textbook on Palliative Care for Children* was published in 2005, and updated in 2012 (Goldman, Hain, & Liben). Also in 1993, the International Work Group on Death, Dying and Bereavement published the *Statement on Pediatric Palliative Care*, the first document to put forward outline basic principles of PPC (IWG, 1993). Not until the end of the decade did the American Academy of Pediatrics publish a position statement on PPC (2000) clearly indicating that PPC was of interest to pediatric medicine. Also within this decade, both the Canadian (CHPCA in 1995) and the American (NHPCO in 1996) hospice and palliative care associations supported bringing groups of individuals together to advocate for PPC. ChiPPS thus came into being in 1998.

Clinically, the 1990s saw the development of several additional hospital-based PPC programs in the UK, the US, Australia, and New Zealand, each with their start in pediatric oncology. In the US, for example, the Pediatric Advanced Care Team (PACT) began as a demonstration project at Dana-Farber Cancer Institute in 1997, and in 2001 expanded to include all children with life-threatening illnesses at Children's Hospital Boston. As hospital-based *Pain and Symptom Teams*, *Comfort Care Teams*, or *PPC Teams* formed, they functioned primarily on a consultative basis providing support and advice to the primary care team in addition to the child and family. As well, professionals and parents began to discuss the need for targeted palliative care programs in neonatal and perinatal populations.

Children's hospices continued to expand in the UK (where they now number nearly 50). In Vancouver, Canada, Canuck Place Children's Hospice, the first free-standing children's hospice in North America, opened in 1995. There are now six children's hospices in Canada, with two additional hospices under construction. Children's hospices also developed in some European nations and in Africa. Bereavement programs for children continued to grow, primarily in western nations, and not necessarily associated with PPC. Arising from the high level of activity of the 1990s were increasingly clear and comprehensive definitions of PPC (ACT, 2009; WHO, 2006).

## The 2000s

The 2000's brought other developments to pediatric palliative care. Established in 2005 and situated in South Africa, the International Children's Palliative Care Network (ICPCN) works with national and regional associations to achieve the best quality of life for children and young people, their families, and carers worldwide. The ICPCN published a Charter of Rights for children with LTC (2008) with the goal to have the Charter accepted and ratified by governments and health departments throughout the world. And, since 2015, ICPCN has spearheaded **global campaigns to increase** worldwide awareness of PPC and to explore what the developed world can do help those in the developing world. Other international growth is evident in the expansion of PPC organizations and conferences (e.g., The First Middle Eastern Conference on PPC in Kuwait and Annual European Conferences on PPC in Rome). Standards documents have been designed to promote a standard, consistent approach to PPC regardless of the location of care delivery (the UK's Together for Short Lives, 2013; The Canadian Hospice and Palliative Care Association, 2006; the Task Force on Palliative Care for Children of the European Association of Palliative Care, 2007) and ChiPPS as part of NHPCO in the US (2009).

Educational programs have been especially well developed in the US in the 2000s. The End of life Nursing Education Consortium (ELNEC), a national initiative to improve palliative care administered by the American Association of Colleges of Nursing, adapted its core curriculum for Pediatrics in 2003 and updated it to include enhanced perinatal and neonatal content in 2009. The ELNEC Pediatric Curriculum Modules are also available as online training through the Hospice Education Network ([www.hospiceonline.com](http://www.hospiceonline.com)). Similarly, EPEC (Education in Palliative and End-of-Life Care), established to provide education for physicians ([www.epec.net](http://www.epec.net)), inaugurated its EPEC-Pediatrics program in 2012. Both ELNEC and EPEC programs are based on a "train the trainer" concept, and both have expanded internationally. Particularly useful for making PPC training accessible and affordable to all who need it is the ICPCN-developed free e-learning program ([www.elearnicpcn.org/](http://www.elearnicpcn.org/)).

Specialization is growing within PPC. Pediatric palliative medicine is now recognized as a subspecialty in the UK, the US, and Canada. The National Board for Certification of Hospice and Palliative Nurses offers certification for hospice and palliative pediatric nurses in the US. Increasingly, specialization is also possible for other disciplines, such as social work. Also in this current decade, perinatal palliative care as a specialty has burgeoned, for example, with the creation of the Pregnancy Loss and Infant Death Alliance and the publication of a neonatal end-of-life protocol that was subsequently circulated worldwide (Catlin & Carter, 2002).

During the 2000s, PPC international development has grown dramatically with new PPC programs in several European nations such as Russia (2010) and Africa (Soweto/Johannesburg), Costa Rica, and Mexico. In Greece, the nation-wide bereavement program of Merimna was expanded to include the first PPC home care service in that country ([www.merimna.org.gr](http://www.merimna.org.gr)). As well, the first free-standing children's hospice in the US, George Mark Children's House, opened in 2004 in San Leandro, California. Another facility for children, partnered with an established hospice, opened in Arizona in 2010. The Children's Hospice International Children's Program of All-Inclusive Coordinated Care (ChiPACC) initiative provided essential pilot studies to foster continued advocacy and initiatives at the state and national levels. Florida, one of the ChiPACC pilot states, implemented a Home and Community-Based Waiver to provide PPC services to medically fragile children. Now Colorado, California, and North Dakota have approved active waivers. As well, Concurrent Care, a provision of the Affordable Care Act implemented in 2010, allows for Medicaid eligible children to receive both hospice and curative care at the same time – something that was a significant barrier for families who could benefit from the services provided by hospice. Currently, NHPCO is hosting a networking teleconference call every other month for state leaders in PPC to help them learn from each other, to provide support for the states trying to get waivers in place, and to insure that concurrent care implementation is supported.

## Research Development

Early in the 2000s, the Institute of Medicine (IOM) published three reports including one that shone a spotlight on the plight of dying children and their families in the US (Field & Behrman, 2003) and called for national attention to address, build, and sustain a robust research agenda in end-of-life/palliative care. In 2010, the evaluative report that reviewed the research in palliative care from 1997-2010, indicated that less than 10% of all research publications focused on PPC. There is still a long way to go to provide research evidence on which to base PPC but considerable progress has been made in many areas.

Despite steadily increasing numbers of research projects, challenges derive from the relatively small population of children and the relatively few PPC professionals. I believe that one path to success is through infrastructure funding that makes it possible for research to occur. For example, the Canadian Institute of Health Research (CIHR) funded nine specialty research groups as Palliative Care New Emerging Teams in 2004. PedPalNET, an interdisciplinary (Medicine, Nursing, Social Work) core of five researchers was the only pediatric palliative care team funded in the competition (Straatman, et al., 2008). The seed money from CIHR enabled the members of the PedPalNET group to secure additional funding totaling nearly \$3.6M (excluding all investigators' salaries that are not covered by research funding in Canada) to support a wide range of multidisciplinary projects across biomedical/clinical questions, psychosocial issues, and health services inquiries. The group received funding to expand and continue work as PedPalAScNet (A Network for Accessible, Sustainable, Collaborative Research in Pediatric Palliative Care) with PPC clinicians across the country – all made possible by the CIHR infrastructure support.

Another successful form of infrastructure support is through the creation of research positions that allow individuals the freedom to conduct and lead research programs, encourage and foster the development of excellence in children's palliative care, and seek to influence national and international services and policy. Examples include the UK's True Colours Chair in Palliative Care for Children and Young People at the University College, London, Institute of Child Health and Great Ormond Street Hospital in 2010; in the US, the Director of Research position with Children's Hospital of Philadelphia's Pediatric Palliative Care Program; and, in Sweden at the Erstra Skondal University College, the Galo Foundation's Professorship in Palliative Care with a Focus on Children and Youths. Such examples may help to convince administrators and funders, in a climate of diminishing resources, of the value of creating infrastructure to support the research and evaluation that is required to provide the basis upon which optimal care can be provided.

### Challenges

Despite the advancement of the field of PPC, a range of barriers and associated challenges has been articulated (Davies, et al., 2008; Liben, Papadatou, & Wolff, 2008). My reflections suggest five challenges.

1. The uncertainty of prognosis and unpredictable disease trajectory that are characteristic of children in PPC, particularly those with LTC, may hamper clinicians' ability to predict treatment responses or overall chances of a child's survival, affect decision-making by both clinicians and parents, discourage the co-existence of "cure versus palliative" thinking, and undermine credibility and trust. They delay referrals to palliative care, hindering conversations in anticipation of when, where, and how next steps might occur. Earlier rather than later discussions allow more time for both clinicians and families to hear, to question, to reflect, and to understand. Indeed, "uncertainty is not something to be avoided, but rather is an inherent dimension of PPC. An uncertain prognosis should serve as a signal to initiate palliative care, rather than to avoid it" (Davies et al., 2008, p. 6).
2. The efficiency-model that currently guides the operation of most health care institutions jeopardizes the operationalization of person-centered or family-centered care despite formal statements proclaiming these concepts as guiding values. As a result, the flexibility of time and effort that is required to attend to the cultural and spiritual needs of children and families is not well supported.
3. The increasing focus on the dominance of the medical model, rather than a truly team-based interdisciplinary approach, presents an additional challenge. Of course, the adoption of pediatric palliative medicine is necessary and integral to furthering the field of PPC, particularly in relation to exploring and developing the underlying mechanisms of the many rare and unusual diagnoses that now fit within PPC and in developing and testing treatments that may eventually ease the suffering of the children with these diagnoses and of their families. But along with the medical approach comes resolute adherence to the scientific model of controlled clinical trials as the gold standard, the quantification of symptoms and interventions. Indeed, these approaches have their rightful place. But optimal PPC exists at the crossroads of the traditional scientific approach and the experience of human beings at what is often the most critical time of their lives. PPC needs to be based upon both science and art where practical and meaningful insights are gained from the bio-medical or psychological approach as well as from the broader humanistic approaches of sociology, history, philosophy, and the person-centered and

family-centered foundations of nursing, social work, and theology. On a personal level, I have found there is a camaraderie among PPC team members that seems rare in other fields; we all share a common philosophy that has person/family-centered care at the core. But the pressures of disciplinary, as well as academic and institutional norms are profound, greatly compounding the personal and professional stress of many who struggle every day to provide optimal PPC – which is, in fact, an additional challenge.

4. Taken together, the foregoing challenges impede the seamless continuity of care across the various dimensions of PPC – particularly respite, transitional, and bereavement care. Where respite care is offered on a regular basis so parents have a break, parents cope better with the demands of caring for their sick child. Respite care is a central aspect of pediatric hospice facilities or home hospice programs, but most parents do not have access to a children's hospice. Periodic admissions to hospital for acute episodes only compound parental responsibilities and worries; having a child in hospital is not respite. The need for respite services has long been documented (ACT 2009). Thus, designating even a few respite beds in acute care settings and developing enhanced home hospice/respite service would facilitate clinicians working across settings to foster the best possible care for families.

Improvements in medical and nursing therapies mean many children with LTC are surviving longer; this trend will continue as medical science advances. Thus, managing the transition of young people from pediatric to adult services must be well coordinated, include the young person and the family in long-range planning, and take into account the young person's developmental and individual needs. One of the few hospices to provide respite for young people is Helen House, now expanded to Helen and Douglas House in Oxford, which opened in 2004. Being able to stay longer in this facility decreases a need for extensive transition services.

Support for grief resulting from the numerous losses that accompany PPC should begin at the time of diagnosis and continue for as long as needed post-death (CHPCA, 2006; EAPC, 2007; NHPCO, 2009). Children's hospices typically offer active grief counseling to families as they encounter the numerous losses that occur along the trajectory of the child's illness. Upon the child's death, families' bereavement needs are met through support groups and other gatherings that families find helpful. Palliative care programs in hospitals seem to pay less attention to the grief of the families in their care, though some hospitals have bereavement follow-up programs whereby sympathy cards are sent to families of children who died, or annual memorial services are held for the families who wish to attend. Social workers or chaplains often do their best to attend to grieving families but must typically focus on the needs of other children in their care and cannot attend to grieving family needs in this regard, particularly after they leave the hospital program. Moreover, little attention is directed to the grief responses of the professionals whose daily work involves repeatedly dealing with issues of loss, with support remaining solely informal among team members. Grief takes time, effort, and patience for those grieving and for helpers, and the current system limits the perception of such activities as efficient use of limited resources.

5. The final challenge exists within the broader society where the certainty of mortality is dealt with through the pervasive presence of violence and death in the news and entertainment media, but where conversation about life's uncertainties surrounding illness, loss, disability, death, and grief is seldom heard and where conversation about children's dying and death is inaudible. Yet, within the field of PPC, such conversations are a reality. All of us in PPC must "spread the word" that death is inherent in human existence and that talking about it helps to ease the burden of hiding or silently harboring this realization.

In conclusion, I believe that the development of ChiPPS has played an integral role in the ongoing evolution of PPC, particularly in the US. The original purpose of the newsletter was to regularly disseminate information about recent developments, programs, activities, and events pertaining to palliative and hospice care for children. Publishing 50 issues of the e-newsletter and e-journal attests to ChiPPS' success in fulfilling that purpose. Moreover, under the tending of its conscientious editors over time, the publication has gone from "disseminating news" to "sharing knowledge" about the care of children with LTI, thereby optimizing the services that families receive. Thanks to the dedication of ChiPPS, I am confident that the next 50 issues will continue to grow and change as PPC itself continues to evolve.

## References

- American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. (2000). Palliative care for children. *Pediatrics*, 106 (2), 351-357.
- Association for Children with Life-Threatening or Terminal Conditions and their Families. (ACT), Royal College of Paediatrics and Child Health. (2009) *A Guide to the Development of Children's Palliative Care Services* (3rd ed). Bristol: ACT.
- Binger, C., Ablin, A., Feuerstein, R., Kushner, J., Zoger, S. Burne S.R., Dominica, F., Baum, J.D. & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on the child and family. *New England Journal of Medicine*, 280, 414-418.
- Ablin, A.R., Binger C.M., Stein, R. C., Kushner, J.H., Zoger, S., & Mikkelsen C. (1971). A conference with the family of a leukemic child. *American Journal of Diseases of Childhood*. 122(4):362-364.
- Bluebond-Langer, M. (1978). *The Private Worlds of Dying Children*. Princeton, NJ: Princeton University Press.
- Burne, S.R., Dominica, F., & Baum, J.D. (1984). Helen House – a hospice for children: Analysis of the first year. *British Medical Journal Clinical Research Education*, 289: 1165-68.
- Canadian Hospice Palliative Care Association. (2006). *Pediatric hospice palliative care: Guiding principles and norms of practice*. Ottawa, Ontario, Canada: Author. Retrieved from [http://www.chpca.net/media/7841/Pediatric\\_Norms\\_of\\_Practice\\_March\\_31\\_2006\\_English.pdf](http://www.chpca.net/media/7841/Pediatric_Norms_of_Practice_March_31_2006_English.pdf)
- Catlin, A., & Cater, B. (2002). Creation of a neonatal end of life palliative protocol. *Journal of Perinatology*, 22930, 184-195.
- Chappell, B. (2007). *Children Helping Children with Grief: My Path to Founding the Dougy Center for Grieving Children & Their Families*. Troutdale, OR: NewSage Press, Inc.
- Corr, C.A., & Corr, D.M. (Eds.) (1985). *Hospice Approaches to Pediatric Care*. New York: Springer.
- Davies, B. (1993). Section editor: Paediatric palliative care. In D. Doyle, G. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine*, (1st ed), pp. 679-733. Oxford: Oxford University Press.
- Davies, B., Sehring, S., Partridge, J.C., Cooper, B., Hughes, A., Phip, J., Amidi-Nouri, A., & Kramer, R., (2008). Barriers to palliative care in children: Perceptions of health care providers. *Pediatrics*, 121, 2822-288.
- End-of-Life Nursing Education Consortium - Pediatric Palliative Care (ELNEC-PPC). (2009). *ELNEC-Pediatric palliative care*. Washington, DC: American Association of Colleges of Nursing. Retrieved from <http://www.aacn.nche.edu/el nec/about/pediatric-palliative-care>
- European Association for Palliative Care; Steering Committee of the EAPC task force on palliative care for children and adolescents. (2007). IMPaCCT: Standards for paediatric palliative care in Europe. *European Journal of Palliative Care*, 14(3), 109-114.
- Field, M.J., & Behrman, R.E. (Eds.) (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington, DC: National Academies Press.
- Goldman, A., Hain, R., & Liben, S. (2012). *Oxford Textbook of Palliative Care for Children* (2nd ed.). Oxford: Oxford University Press.
- International Children's Palliative Care Network. (2008). *The ICPCN Charter of Rights for life limited and life threatened children*. Assagay, South Africa: Author. Retrieved from <http://www.icpcn.org/icpcn-charter/>
- International Work Group on Death, Dying and Bereavement: (1993), Palliative care for children. *Death Studies*, 17, 277-280.

- Lauer, M.E., Mulhern, R.K., Wallskog, J.M., & Camitta, B.M. (1983). A comparison study of parental adaptation following a child's death at home or in the hospital. *Pediatrics*, 71: 107-112.
- Lauer, M.E., Mulhern, R.K., Bohne, J.B., & Camitta, B.M. (1985). Children's perceptions of their sibling's death at home or in hospital: The precursors of differential adjustment. *Cancer Nursing*, 8, 21-27.
- Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *Lancet*, 371: 852-64.
- Martinson, I.M., Moldow, D.G., Armstrong, G.D. Henry, W.F., Nesbit, M.E., & Kersey J.H. (1986). Home care for children dying of cancer. *Research in Nursing and Health*, 9, 11-16.
- Moldow, D., & Martinson, I.M. (1980). From research to reality - Home care for the dying child. *The American Journal of Maternal Child Nursing*, May/June, 51, 159-166
- National Hospice and Palliative Care Organization. (2009). *Standards of practice for pediatric palliative care and hospice*. Alexandria, VA: Author. Retrieved from [http://www.nhpco.org/sites/default/files/public/quality/Ped\\_Pall\\_Care%20Standard.pdf](http://www.nhpco.org/sites/default/files/public/quality/Ped_Pall_Care%20Standard.pdf).
- Papadatou, D. & Papadatos, C. (Eds). (1991). *Children and Death*. New York: Hemisphere.
- Schorsch, A. (1979). *Images of childhood: An illustrated social history*. New York: Mayflower Books.
- Spinetta, J.J., Rigler, D., & Karon, M. (1973). Anxiety in the dying child. *Pediatrics*. 52, 841-845.
- Straatman, L., Cadell, S., Davies, B., Siden, H., Steele, R. (2008). Paediatric palliative care research in Canada: Development and progress of a new emerging team. *Paediatric Child Health* 13:591-594
- Together for Short Lives. (2013). *Standards framework for children's palliative care* (2nd ed.). Bristol, UK: Author. Retrieved from [http://www.togetherforshortlives.org.uk/assets/0000/5003/Standards\\_framework\\_update\\_2013.pdf](http://www.togetherforshortlives.org.uk/assets/0000/5003/Standards_framework_update_2013.pdf)
- Waechter, E.H. (1971). Children's awareness of fatal illness. *American Journal of Nursing*, 71, 1168-1172.
- This article has been adapted from Davies, B. (2015). Palliative care for children. In J. Stillion & T. Attig (Eds.) *Death, Dying and Bereavement: Contemporary Perspectives, Institutions and Practices*. New York: Springer Publishing, pp. 165-179

## REFLECTIONS ON THE GROWTH AND DEVELOPMENT OF CHILDREN'S PALLIATIVE CARE

**Stephen R. Connor, PhD**

**Former VP for research and development at NHPCO**

**Executive Director**

**Worldwide Hospice Palliative Care Alliance**

**[sconnor@thewhpca.org](mailto:sconnor@thewhpca.org)**

One of my first duties as the vice president of NHPCO (then NHO) in 1998 was to take responsibility for planning the first international pediatric palliative care conclave from the former VP Galen Miller. I was especially keen that this important event, the first of its kind, be very successful. I came to NHPCO with 22 years' experience running (four) hospice programs throughout the U.S. and had always insisted that the programs I served always would admit children.

The conclave brought pediatric palliative care clinicians together from all over the world and had been organized at the request of some of the major figures in the field who wanted NHPCO to be a convener and supporter of these early efforts to build the field of palliative care for infants, children, and adolescents. During the conclave it was quickly recognized that there was very little literature, curricula, standards, or evidence to support this new field and that access to services was very limited. A steering group of six experts and myself planned the event which was held in conjunction with the NHPCO annual conference in Dallas

Texas in 1999. The 36 conclave attendees formed into several working groups to begin to address the work needed. The project was titled CHIPPS (Children's International Project on Palliative/Hospice Services)

**CHIPPS Publications**

The first of several important publications to come out of CHIPPS was the *Compendium of Pediatric Palliative Care (2000)*. The *Compendium* was essentially an effort to pull together all the available resources on the field. It included four main sections and four appendices. The sections were: (1) pediatric palliative care services – principles of implementation; (2) communications, ethics, & decision making; (3) management of pain and other symptoms; & (4) psychosocial & spiritual care. The appendices matched the main sections and included many practical resources to support the knowledge put forward.

The second major publication was the *Education and Training Curriculum for Pediatric Palliative Care (2003)* – The curriculum was developed primarily by Drs. Danai Papadatou, Charles Corr, Gerri Frager, and Maria Bouri. It included a set of 14 training modules in four sections:

1. Modules related to comprehensive pediatric palliative care
  - a. Principles of pediatric palliative care (PPC)
  - b. Applied PPC: Options and benefits of PPC in a variety of settings
  - c. Organization & management of PPC services
2. Modules related to the care of children with life threatening conditions
  - a. Serious illness and dying in the context of childhood and adolescent development
  - b. Assessment and management of pain and other distressing symptoms
  - c. Psychosocial, educational, and spiritual concerns and needs of dying children and adolescents
  - d. Verbal and symbolic communication and interaction with children and adolescents
3. Modules that related to the care of family and significant others
  - a. Concerns and needs of family members and significant others when a child or adolescent is seriously ill or dying
  - b. The mourning process of parents, siblings, and significant others following the death of a child or adolescent
  - c. Support of bereaved parents, siblings, grandparents, and significant others
4. Modules that related to health care providers and the community
  - a. Communications and decision making during crisis situations and end-of-life care
  - b. Interdisciplinary team approach
  - c. The impact of providing pediatric palliative care on health professionals
  - d. Raising community awareness and training in pediatric palliative care

The curriculum also included handouts, bibliography, and appendices.

The third publication was *Caring for Kids: How to Develop a Home-Based Support Program for Children and Adolescents with Life-Threatening Conditions (2004)* – This manual was focused on how to develop home-based pediatric palliative care services built around a set of 16 imperatives:

- |                                   |                                    |                           |
|-----------------------------------|------------------------------------|---------------------------|
| 1. Assessing community resources  | 7. Financial and business planning | 13. Internal education    |
| 2. Administrative mission         | 8. Fundraising opportunities       | 14. Supporting staff      |
| 3. Philosophy of pediatric care   | 9. Pediatric champions             | 15. Commitment to quality |
| 4. Compassion for special needs   | 10. Interdisciplinary teamwork     | 16. Bereavement support   |
| 5. Partnerships and relationships | 11. Medical direction and guidance |                           |
| 6. Community outreach             | 12. Operational policies           |                           |

### Other Publications and Activities

ChIPPS has made significant contributions to the field of children's palliative care along with other very notable groups, including Children's Hospice International, Together for Short Lives, the Initiative for Pediatric Palliative Care, and most importantly the International Children's Palliative Care Network (ICPCN). The ICPCN has been successful in bringing together all the major groups working on this field and has become an influential international non-governmental organization advocating for children's palliative care globally.

### ICPCN

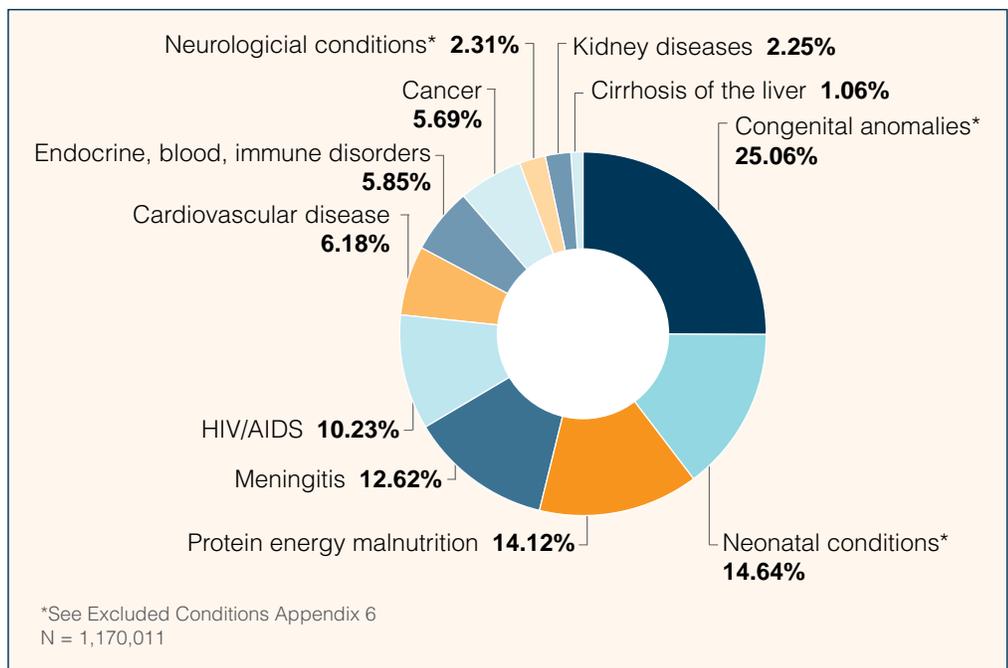
The ICPCN ([www.icpcn.org](http://www.icpcn.org)) is now the hub for children's palliative care globally. ICPCN has members in 120 countries and provides extensive free resources including on-line courses, global advocacy for CPC, conducts CPC research, manages the international edition of ehospice ([www.ehospice.com](http://www.ehospice.com)), and hosts many events and special projects including an annual conference. They also have led efforts to measure the need for and development of children's palliative care globally.

### Measuring the Need for Children's Palliative Care

Several efforts to publish estimates of the global need for children's palliative care (CPC) have been undertaken in recent years. The first of these was the *Global Atlas of Palliative Care at the End of Life (2014)*,<sup>i</sup> which used WHO mortality data to create a minimum estimate. The second was an effort funded by UNICEF and several trusts to develop and estimate using prevalence data (Connor, Downing, & Marston, 2017).<sup>ii</sup> The third and most recent report is a *Lancet Commission Report*<sup>iii</sup> that uses health related suffering as a way to estimate the need.

The *Global Atlas*<sup>1</sup> is a joint publication of the WHO and the Worldwide Hospice Palliative Care Alliance that attempted for the first time to estimate the global need for palliative care for both adults and children. Twelve diagnostic groups were identified as needing palliative care and estimates were made based on WHO mortality data for 2012. As a result, 1,170,011 children aged 0-19 were identified as needing palliative care at the end of life. The use of mortality data underestimates the need for CPC. A child may need palliative care for one hour or twenty years. Children are more resilient than adults and determining prognosis is more challenging.

**Figure One: Distribution of children in need of palliative care at the end of life by disease groups**



The second effort to estimate the need for CPC was led by ICPCN with funding from UNICEF and several other foundations, and primarily used prevalence data, which gives a more population-based view of the need. The same diagnostic categories were used as in the *Global Atlas* report but prevalence data was obtained from the Institute for Health Metrics and Evaluation at the University of Washington, the home for the global burden of disease studies. As a result of this research<sup>2</sup> two estimates were derived. One was for the total need for CPC including children that needed some palliative care approaches and a second estimate for the number of children needing specialized palliative care services, both before and at the end of life. The total global need was over 21 million while the specialized need was over 8 million.

The third research report estimating the need for palliative care for both children and adults was the *Lancet Commission Report*<sup>3</sup> which estimated that out of over 61 million people needing palliative care worldwide 5.3 million were children between the ages of 0-15. The *Lancet* report uses a new measure of serious health-related suffering along with mortality data to derive estimates. While we do not know precisely how many children need palliative care, we do know that it is substantial. The *Global Atlas* report probably underestimates the need, but if we compare the *Lancet* estimate (5.3M) to the ICPCN estimate of need for specialized care (8M) they are somewhat close considering that ICPCN used 0-19 while *Lancet* used 0-15.

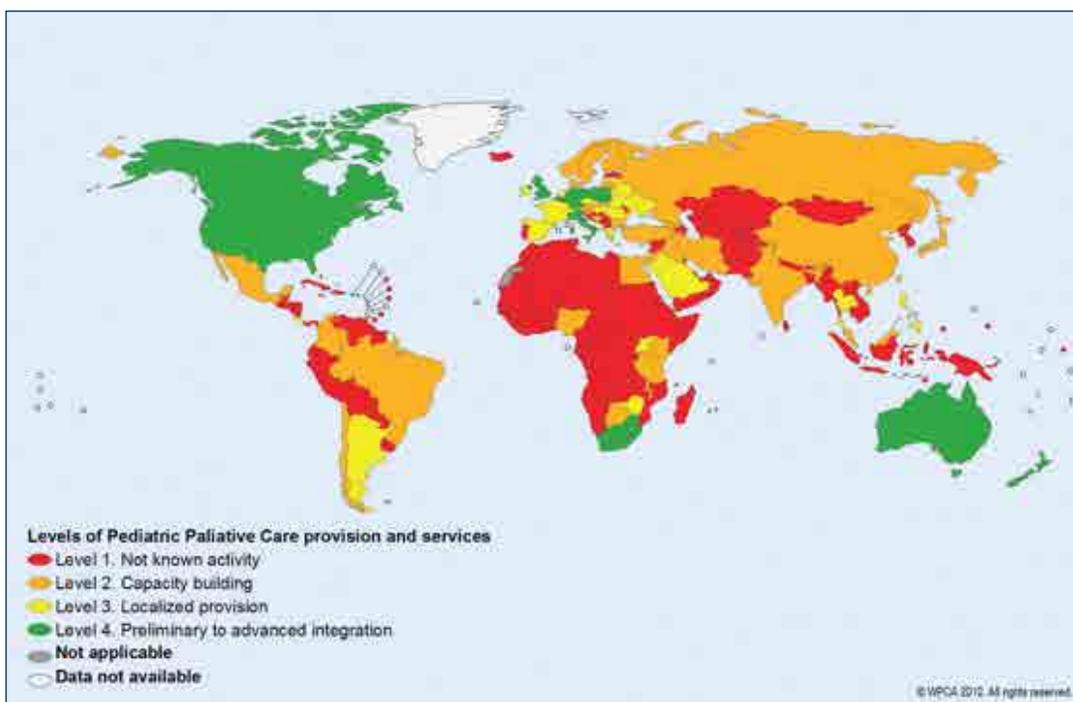
All three reports also neglect some groups of children with complex needs that are long term, such as those with cerebral palsy & Down syndrome that benefit from a palliative approach even though they may have good survival. Fortunately, we are getting closer to answering this question, which is so crucial to planning and advocating for children's palliative care.

### Mapping Levels of Children's Palliative Care Globally

In addition to understanding the need for children's palliative care, it is also important to assess the capacity to provide CPC globally. A mapping of levels of CPC development was undertaken by the ICPCN using a 4-level schema (Figure 2).

1. No known children's palliative care and no one working on the problem
2. No CPC but some champions interested in developing programs, capacity building
3. Some children's palliative care in operation but with limited reach, localized provision.
4. A community of CPC providers that are beginning to become integrated into mainstream health care systems. Preliminary or advanced integration.

**Figure Two: Levels of Pediatric Palliative Care Development**



## Conclusion

ChiPPS has made major contributions to the field of pediatric palliative care including many influential publications and an exceptional continuing newsletter on key issues in the field. While there is still a long road ahead the early pioneering work of ChiPPS set the stage for many advancements in the field and continues to be a source of inspiration in the USA and globally.

## References

- <sup>i</sup> Connor S, & Sepulveda C. (Eds) (2014) *Global Atlas of Palliative Care at the End of Life*. London UK, Geneva CH: Worldwide Palliative Care Alliance and World Health Organization. <http://www.who.int/cancer/publications/palliative-care-atlas/en/>
- <sup>ii</sup> Connor S, Downing J, & Marston J. Estimating the global need for palliative care for children: A cross-sectional analysis. *J Pain Symptom Mgmt*, (2017);53(2):171-77
- <sup>iii</sup> Knaul F, Farmer P, Krakauer E, de Lima L, Bhadelia A, Xiaoxiao JK, Arreola-Ornelas H, Dantes OG, Rodriguez NM, Alleyne G, Connor, S, Hunter D, Lohman D, Radbruch L, Saenz R, Atun R, Foley K, Frenk J, Jamison D, & Rajagopal MR. (2017). Alleviating the Access Abyss in Palliative Care and Pain Relief: An imperative of universal health coverage: Report of the Lancet Commission on Global Access to Palliative Care and Pain Control. *Lancet* <http://www.thelancet.com/commissions/palliative-care>

*Editor's note: Images in this article are copyrighted by the Worldwide Hospice Palliative Care Alliance and are used here by permission.*

## REFLECTIONS ON CHIPPS: CELEBRATING A ROAD WELL-TRAVELLED AND OPENING UP TO NEW CHALLENGES

**Danai Papadatou, PhD**

**Professor of Clinical Psychology**

**School of Nursing**

**National and Kapodistrian University of Athens**

**Athens, Greece**

[dpap@nurs.uoa.gr](mailto:dpap@nurs.uoa.gr)

The invitation came from NHPCO: Thirty-one professionals who were contributing to the development of pediatric palliative care in their country would gather in Dallas, Texas, in November 1998. The goal of that meeting was to exchange knowledge and experiences, and set priorities so as to move palliative care for children forward. ChiPPS (The Children's International Project on Hospice /Palliative Services) was the project to undertake for such an ambitious goal.

I vividly remember the thrill I felt when we all met and set specific tasks for working both in small groups and together as a body of concerned professionals. I knew most of the participants, because 10 years before, along with my father, a professor of Pediatrics at the University of Athens, we had co-organized with the help of Chuck Corr, the 1st International Conference on Children and Death, in Greece. For the first time ever, approximately 500 professionals and 23 invited speakers from 17 countries had gathered to share knowledge and experiences on pediatric palliative care, childhood bereavement support, and death education. During that meeting, new collaborations were born, and one more book was subsequently edited (Papadatou & Papadatos, 1991) to add to the valuable editions that were available at that time (Corr & Corr, 1985; Corr & McNeil, 1986; Wass & Corr, 1994).

When ChiPPS emerged, several initiatives were already in place, and the Dallas meeting was instrumental to consolidate some of the existing knowledge and move the field forward. The gathering allowed for a rich exchange of experiences, practices, ideas for research, education, and implementation of services. Valuable documents, compendiums, and research projects were initiated and completed in the years that followed. They became precious resources and contributed to the dissemination of knowledge, clinical experience, and research across the world.

I then had the privilege to collaborate with Chuck Corr and Geri Frager on the *Training Curriculum in Pediatric Palliative Care* (NHPCO, 2003). Our project started in Dallas, continued in Florida at Chuck's home, and was completed through the exchange of multiple emails between USA, Canada, and Greece. It gave us the opportunity to document our experience in teaching pediatric palliative care, and helped locate and organize valuable educational materials (e.g., articles, videos, didactic and experiential exercises), which became widely available.

I am not aware of the feedback that NHPCO received from individuals and organizations who benefited from the dissemination of the *Compendium on Pediatric Palliative Care* and of the *Training Curriculum in Pediatric Palliative Care*, but both have been an inspiration to me. A few years before ChiPPS, along with colleagues, I had founded "Merimna" ('care' in Greek), a non profit organization for the care of children and families facing illness and death ([www.merimna.org.gr](http://www.merimna.org.gr)). We initially focused on providing, free of charge, bereavement services through the *Childhood and Family Bereavement Support Center* (Papadatou, 2012), along with *Training Programs* for clinicians on supporting grieving children and families, as well as on pediatric palliative care. It is only in 2010 that the ground was fertile, to open up the *Pediatric Palliative Home Care Service* (ChiPPS Newsletter, no.21, 2010), which still remains the only available resource for seriously-ill children in Greece. Today, we struggle to secure funds in the midst of a long-lasting socioeconomic crisis, and continue to set goals in the hope to make our services more widely available to Greek, migrant, and refugee seriously-ill children who live under challenging or dire conditions.

I have been most fortunate in life to have multiple opportunities to share my clinical, educational, and research experience with colleagues around the world, who are developing or have integrated pediatric palliative care in the health care systems of their country. I have been most impressed by their dedication, ingenuity, and creativity in their efforts to open pathways in territories filled with obstacles. Even though much has been accomplished over the past three decades in pediatric palliative care, there are many more challenges ahead that require our relenting perseverance and collective coordination:

**1. Stronger advocacy for accessibility to palliative care services for every seriously-ill child and family in the world.**

We must continue to highlight the *right of every child* with a life-limiting condition to have access to palliative care services, and be relieved from serious health-related suffering which may be associated with illness or injury of any kind. Failure to provide palliative care constitutes a cruel, inhumane approach towards youngsters with a limited life span. More than 5.3 million children aged 15 years or younger can benefit from palliative care, while at least 2.5 million die in need to relieve their pain and suffering. Given that 98% are children from developing countries, we must find more effective ways to have their voices be heard, and exert pressure on governments to develop comprehensive health policies that address the complex needs of children with life-limiting conditions and of their family members (EAPC, The Prague Charter, 2009). We have still much to learn from families, professionals, and organizations that have been instrumental in overcoming barriers and contributed to the institution of legal, health care systems, and policies for the provision of high quality pediatric palliative care services in diverse cultural settings. Their successes and failures are sources of valuable wisdom from which we can learn as we strive to make a difference.

**2. Revision of the philosophy and principles of pediatric palliative care and their relevance to children and families of different cultural origins.**

We need to expand the *family-centered palliative care model*, which focuses exclusively on the physical, psychosocial, and spiritual needs and concerns of both children and family members, disregarding to a great extent, the impact of such care on professionals, on the team's functioning and ability to manage distress, and on the work culture of the organization or health care setting. Moreover, it neglects the broader social, cultural, religious influences that affect the quality of care. I believe we should adopt a more systemic approach that is "relationship-centered" and acknowledges the reciprocal influence among those who provide and those who receive pediatric palliative care in a given socio-cultural context (Papadatou, 2009).

Western models and principles of care which have been developed in the UK and North America and which value disclosure and honesty, patient autonomy and involvement in decisions, and open expression of feelings, concerns, and thoughts, may not be appropriate in other cultures in which a protective approach towards children is adopted, decisions are assumed by one family member or senior adults, and personal feelings, thoughts, and desires remain private out of children's respect to their parents and family elders.

**3. Training and education for professionals seeking different levels of expertise.** The EAPC (European Association for Palliative Care) proposes three distinct levels of education in children's palliative care, depending on the professionals' level of involvement in the delivery of palliative care (Downing et al., 2014). However, several obstacles prevent accessibility, affordability, and sustainability of courses which are rarely evaluated with regard to their outcomes. "Training the trainers" involved in educational programs is imperative so as to provide knowledge and skills, as well as opportunities for the development of attitudes that enhance meaningful living and dignified dying. I have reservations about post-graduate programs that offer specialized degrees on pediatric palliative care through distance learning. Teaching communication skills, experiencing interdisciplinary team work, and managing challenges in hospital settings, community-based services, and on the field (e.g., in refugee camps), requires a teaching context in which capacity building is enhanced and evaluated by experienced instructors. In an ideal educational setting, all undergraduate and post-graduate students should be offered opportunities to accompany children, adolescents, and/or adults who strive to live to the fullest, while dying from an incurable disease. Clinical experience on how to develop meaningful relationships, how to address intimacy issues, how to respect diversity in decisions, and how to enhance awareness on personal and team responses, are most valued both by clinicians as well as by children and family members who benefit from a humane and dignified approach to care.

**4. The provision of pediatric palliative care after a mass disaster and/or humanitarian crises.** Forced displacement, war, conflict, environmental disasters, and major national socio-economic crises have a devastating impact on health care systems and deeply affect children with chronic and life-limiting conditions and their families. Living conditions may be so adverse that access to food, shelter, safety, and pain-relieving medication may become a top priority. In these situations, palliative care must be provided by field and humanitarian workers, who do not have the skills to identify and address a broad range of needs among seriously-ill and injured children, and who may also be orphaned or separated from their family support network.

For palliative care to have a place in humanitarian responses, obstacles must be identified and collective actions must be undertaken to bring about changes. While humanitarian work focuses on saving lives, a new ethos is necessary to consider ways to ease the suffering of children who are dying, have life-threatening conditions, or suffer serious injury. The need to train field workers and include a palliative care specialist in humanitarian teams is only a starting point. Access to an affordable "Essential Package of Palliative Care" can alleviate much of the inequitable and preventable burden of suffering that is experienced under adverse living conditions (Lancet Commission Report, 2017). Moreover, standards and guidelines for the provision of palliative care during humanitarian crises, must become a top priority since we all live in a world that is faced with the largest ever, forced displacement of populations, and is exposed to multiple environmental and human-induced disasters.

**5. Development of standards of team functioning and guidelines for addressing stress prevention and management.** Even though the field of pediatric palliative care has given some attention to the stress of professionals who care for children and families through the life-threatening illness, little is known about how stress impacts teams, teamwork, and organizational culture. I believe that we must go beyond addressing stress at an individual level through self-care strategies, and think more systemically by considering how stress affects teams and palliative care organizations, which are responsible to act in ways that reduce the risk of adverse consequences and enhance resilience for staff members. Moreover, we must develop written policies with respect to the prevention and ongoing support offered to staff members who have been adversely impacted by palliative care and family bereavement.

**6. Twinship between organizations, services, and teams** across the world in order to benefit from the exchange of knowledge and the implementation of shared projects in different cultural contexts. This collaboration may enrich all parties involved, so as to adequately address the needs of children, families, professionals, and communities, and to promote knowledge through research on biomedical and psychosocial issues affecting children, families, and professionals.

The ChiPPS e-newsletter has been instrumental in the dissemination of information about existing and new programs around the globe, and has built bridges among families and professionals. May it continue to address those issues and inspire us all to make a difference and improve care for children with a life-limiting condition and for their families, and may it contribute to a world that is more humane.

## References

- Corr, C. A. & Corr, D. M. (Eds.). (1985). *Hospice approaches to pediatric care*. New York: Springer.
- Corr, C. A. & McNeil, J. N. (Eds.). (1986). *Adolescence and death*. New York: Springer.
- Downing, J., Ling, J., Benini, F., Payne, S., Papadatou, D. (2014). A summary of the EAPC White Paper on core competencies for education in paediatric palliative care. *European Journal of Palliative Care*, 21, 5, 245-249.
- European Association for Palliative Care (EAPC) (2009). *The Prague Charter*. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=YGvfGW2iIn4%3D&tabid=1871>
- Papadatou, D. (2009). In the face of death: *Professionals who care for the dying and the bereaved*. New York: Springer
- Papadatou, D. (2012). Merimna: The Society for the Care of Children and Families Facing Illness and Death. *Grief Matters*, 15, 3, 64-69.
- Papadatou, D. & Papadatos, C. (Eds.) (1991). *Children and death*. Washington D.C: Hemisphere Publ. Co. & Taylor and Francis
- Papadatou, D., Corr, C., Frager, G., & Bouri, M. (2003). *Training curriculum in pediatric palliative care*. Alexandria, Virginia: National Hospice and Palliative Care Organization
- The Lancet Commission Report* (2017). Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage. [www.thelancet.com](http://www.thelancet.com) Published online October 12, 2017 [http://dx.doi.org/10.1016/S0140-6736\(17\)32513-8](http://dx.doi.org/10.1016/S0140-6736(17)32513-8)
- Wass, H. & Corr, C. A. (Eds.) (1984). *Helping children cope with death: Guidelines and resources*. Washington DC: Hemisphere.

## REFLECTIONS ON CHIPPS: FROM THEN TO NOW

**Stacy F. Orloff, Ed.D., LCSW, ACHP-SW**

**Vice President, Innovation and Community Health**

**Empath Health**

**Clearwater, FL**

[stacyorloff@empathhealth.org](mailto:stacyorloff@empathhealth.org)

I was amazed when asked to contribute a reflection to the 50th issue of the ChiPPS e-Journal. How is it possible that this is our 50th issue? So much has happened over the last 20 years. There is much I am proud of when I consider my early involvement with ChiPPS; however I am the most proud of how different the field of pediatric hospice and palliative care looks from the initial ChiPPS conclave in 1998.

If you allow me to reminisce for a moment... My involvement with ChiPPS began in 1998, at our first conclave in Dallas Texas. There was a small group of us at that initial conclave in 1998. Our initial invitation included colleagues from across North America and around the world. In fact, many of our initial key ChiPPS leaders are Canadian. We learned much from them and their early innovative efforts to care for ill children and their families. Our international focus has been maintained to present.

I participated in several of our workgroups and initial projects such as our White Paper, *Compendium of Pediatric Palliative Care*, and our education curriculum published and disseminated through NHPCO. I clearly remember when we published the very first e-newsletter. I accepted a leadership role with ChiPPS and served as co-chair for ten years. What an amazing professional opportunity for me to work alongside some of the brightest and most prolific clinicians, researchers, and academics in the field.

As I consider the last 20 years and all that's been accomplished, I'd like to briefly highlight the accomplishments we shared at the 2008 NHPCO Clinical Team Conference.

Our mission:

- Make the best-known practices in pediatric palliative care more widely available to care providers
- Increase the availability of state-of-the-art services to families

Our accomplishments the first ten years included:

- Pediatric focus at national conferences
- Educational resources – professional and consumer
- E-newsletter
- Educational resources – professional and consumer

ChiPPS created materials included:

- Pediatric Standards of Care
- ChiPPS educational materials for providers:
  - Educational Curriculum
  - Compendium
  - How to Develop a Home-Base Support Program
- Caring Connections educational materials for families
- Pediatric training for providers:
  - Pediatric Intensive at NHPCO's CTC
  - E-Online and Audio Web Seminars

Wow! What a difference we made in our first ten years. And now, 20 years since we held our very first ChiPPS conclave there are many options to attend pediatric hospice and palliative care conferences. Major peer-reviewed journals regularly include articles about pediatric hospice and palliative care. Educational materials for clinicians are plentiful. There are many different listservs and social media resources to communicate with colleagues around the world. We've come a long way!

It may be hard to remember from where we came. With pride, I'd like to offer a heartfelt thank you to the early ChiPPS pioneers. Without their dedication and commitment I don't believe our field would have advanced as quickly as it did.

## **MUSINGS ON THE EVOLUTION OF CHIPPS AND THE E-JOURNAL**

**Suzanne S. Toce, MD**

**Retired Neonatologist**

**Gundersen Health System**

**La Crosse, WI**

**[tocess@gmail.com](mailto:tocess@gmail.com)**

I've been associated with perinatal and pediatric palliative care (PPC) since the mid 90's and with ChiPPS since 1997. I guess that is why the editors asked me to write on the occasion of our 50th issue. As I've been on the E-Journal group for eons, I didn't feel as though I could refuse!

Here's the backstory... I'm a neonatologist. As a fellow in the late 70's, I had a newborn with an ethical challenge and consulted with Dr. Norman Fost who had just finished his master's degree in law, medicine, and ethics. I was hooked. When I finished my fellowship and started as a faculty member at Saint Louis University, Cardinal Glennon Children's Hospital, in 1980, I had another ethically challenging baby. This led to my founding the hospital's first bioethics committee. No one told me that I couldn't. By the early 90's, it was obvious to those of us on the ethics committee that we were consistently seeing infants, children, and adolescents where the parents were requesting life-prolonging treatments that the health care providers felt was no longer beneficial. In general, these children were noncommunicative. I led a team looking at advance care planning for these medically complex children. The goals were to facilitate discussion of goals and develop strategies to meet these goals. The

care plan was then documented on an advance care planning order set (a paper one, no less!). In the midst of this pilot project, Sr. Judy Caron, the head of our ethics committee, was informed by two different people about the call for proposals by the Robert Wood Johnson Foundation (RWJF) Excellence in End of Life Care project. We got a group together and applied. Of 26 programs funded from >700 applicants, only 2 were pediatric. One was our Footprints Program. No one told us that we couldn't get a RWJF grant! This introduction to pediatric palliative care was indeed a life-changing event. The RWJF team got me involved in the small group that evolved into ChiPPS and eventually became part of NHPCO. I was part of the "executive" team at ChiPPS starting in 1997.

When I started in pediatric palliative care in the 90's:

- I knew all the PPC physicians in North America and could count them on one hand (OK, maybe two hands...).
- There were no PPC fellowship programs. I actually briefly thought about going to Australia to study but that seemed hard with a career, husband, and two children.
- While there were some interest groups, there was no obvious home for PPC professionals. Did we belong with pediatrics or palliative care?
- There was no educational pathway for PPC health care providers. EPEC and ELNEC, and their pediatric versions, came later.
- There were few pediatric-specific quality or outcome standards.
- There were no practice guidelines.
- There were few pediatric pain and symptom assessment tools

The PPC environment at the time was like a hotbed of thinking, collegiality, interdisciplinary hard work, and innovation (and, of course, frustration!)

When I think about the early impact of the RWJF Promoting Excellence in End of Life Care program and ChiPPS/NHPCO on the growth and development of PPC, I wonder...

Is the model a: Springboard? A catalyst? Raindrops on a pond?



It is definitely raindrops: ever spreading outward then overlapping and interacting with others.

With the support of RWJF and ChiPPS, I was able to "network" and collaborate with local, regional, and national PPC programs and providers to further model development, PPC education, and development of quality standards. There were some very amazing and helpful health care professionals from many disciplines that supported me in this journey. I am eternally grateful to their support and guidance. Organizations such as NHPCO, the American Academy of Pediatrics Section on Hospice and Palliative Medicine, RWJF, and many other professional organizations have supported me and others in the field. And of course, the children and their families were perhaps the best educators of all.

“Are we there yet???”



We have come a long way, but we are not “there yet.” What indicators might inform us that we are “there”?

- **Integrated** PPC with routine care at the level appropriate to the needs of the child and family
- **Palliative care = good care**
  - All providers educated in basic PPC
  - Access to specialty pediatric palliative care when indicated
  - Agreed upon triggers for automatic involvement of or referral to the PPC team
- Redefine “success” and “hopes” when a child is deteriorating and/or dying
- Establish secure access to PPC regardless of site of care
- Ensure appropriate funding for care and for professional education
- Support general PPC education included in curriculum for pediatricians starting in residency and continuing through fellowship in all subspecialties. Comparable education for other disciplines.
- Support of strong PPC medical fellowship programs with board certification
- Enrich and implement PPC professional education such as pediatric ELNEC for nurses and EPEC education for physicians
- Support national, regional, state and community interdisciplinary networks of PPC providers
- Develop broad, flexible treatment guidelines
- Develop documentation that supports child and family care, continuity and consistency of care, and quality assurance
- Support PPC research (please see article in this issue by Hal Siden MD)
- Develop standardized PPC quality measures including for:
  - Pain and symptom assessment and management
  - Quality of life
  - Child and family satisfaction with care
  - Function
  - Assessment and management of psychosocial and spiritual issues
  - Decisional support
  - Epidemiology
  - Sites of care
  - Continuing and consistency of care across providers and sites of care
  - Education and training of care providers
  - Access to care
  - Support of the family including siblings and grandparents
  - Bereavement support

In my retirement, I miss actively being involved in the lives of children and their families, and collaborating with phenomenal colleagues. I remain with the ChiPPS E-Journal group and feel that the group continues to enrich my life. I enjoy the interaction and collaboration with such an eclectic thoughtful group of individuals. And I continue to contribute articles. My volunteer work is doing facilitated advance care planning conversations, mostly with individuals at the opposite end of the age spectrum than the newborns and infants that I dealt with during my professional career. I look forward to the next 50 issues of ChiPPS as it supports the continued growth and development of pediatric palliative care.

### CHIPPS - CELEBRATING 50 E-JOURNALS

*Marcia Lattanzi Licht, LHD, RN, LPC*

Psychotherapist, Educator

Boulder, Colorado

[marciaell@aol.com](mailto:marciaell@aol.com)

Fifty issues of the ChiPPS E-Journal is truly a reason to celebrate! A group of professionals from across North America, and initially, internationally, brought significant energy and dedication to the development of a network that would bring together and foster communication among Pediatric Palliative Care and Hospice professionals. My involvement in ChiPPS from its beginnings creates a significant sense of gratitude for the consistent commitment of a dedicated and vibrant group of pediatric palliative and hospice care providers.

Margaret Mead said, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." A small group of well-respected pediatric palliative and hospice care professionals pulled together to create ChiPPS, a national collaborative for pediatric palliative and hospice care. The initial efforts were strongly supported by the National Hospice and Palliative Organization under the leadership of Galen Miller. Galen's nephew, Travis, died of leukemia, and Galen's firm dedication to ChiPPS was a crucial element in its founding, and in securing the ongoing support of NHPCO.

So much of the ChiPPS story parallels the beginning of the North American Hospice Movement. In the early stages of the hospice movement, professionals and volunteers in locations across North America came together with the goal of offering better care for people who were dying and for their families. This care reflected the needs and expressed wishes of individuals and families coping with end-of-life challenges. In a parallel way, visionary pediatric palliative and hospice care providers raised their voices to advocate for greater collaboration around advancing access and excellence in care for children facing life-limiting conditions. The same dedication that fueled the beginnings of hospice in North America led to the fervent desire to advance excellence in pediatric palliative and hospice care. And, like Galen Miller, many of the people involved in establishing ChiPPS had personal or professional experiences that left not only an imprint on them, but also created a dedication to better care for children and their families.

Three elements became central to ChiPPS from the outset, and also parallel the origins of the hospice movement. First, there was a significant level of **Passion** involved in both the beginnings of hospice and the beginnings of ChiPPS, with its focused attention on access to and excellence in Pediatric Palliative and Hospice Care. Something in each of us called us to this work. Children facing life-limiting illnesses deserve our best efforts and the most informed and excellent care possible.

The second element that echoes the early establishment of hospice care is the commitment to **Networking**. It takes a community of family, their support system, and professional and volunteer care providers to address the complex needs of a child facing life-limiting illness. Symbolically, standing behind the professionals delivering care to children is the group of colleagues providing care to children in similar circumstances all across the land. The sharing of information and learning with colleagues has been one of the hallmarks of ChiPPS. And, the E-Journal has been a crucial element in maintaining and sustaining that ongoing, shared learning. While NHPCO continues to support the dissemination of the ChiPPS E- Journal, along with an ongoing clinical conference focus on Pediatric Palliative and Hospice Care, the effort continues to be sustained by

ChiPPS volunteers. Chuck Corr and Christy Torklidson have expertly and steadfastly led the journal throughout its 50 issues. Contributors to the ChiPPS E-Journal continue to willingly and generously share their knowledge and experience with colleagues. That spirit of advancing care is a cardinal element of ChiPPS success. The E-Journal is at the heart of that ongoing impact and success.

The third important element involved in ChiPPS entails the concept of “**paying it forward.**” ChiPPS is a solid example of the historic concept of “paying it forward,” which dates back to an ancient Greek play as well as the writings of Benjamin Franklin. Paying it forward represents the obligation for a beneficiary to repay generosity to others, rather than to the original benefactor. Communication with colleagues offers us pathways of ongoing support that is sustaining for Pediatric Palliative and Hospice Care providers. In some fashion, we are all “paying it forward” with each other, and with the children and families we serve.

So much of the work we do professionally reverberates from our personal/professional experiences and strongly-held beliefs. That dimension leads to the passion, networking, and “paying it forward” elements that I see as an important part of ChiPPS establishment and ongoing work.

There are many contributions I consider meaningful as I reflect upon my more than 40-year hospice and palliative care career. My involvement in ChiPPS stands out as a great source of meaning. When I experienced the traumatic death of my 17-year-old daughter, Ellen, I found myself turning to trusted colleagues in the field for support and information that would help the grieving young people in our circle. The bereaved parents I had worked with for years offered me a model for carrying the pain of losing a child. My commitments have always been to family-centered care and grief services. While we are all deeply committed to caring well for children and minimizing their struggles, the suffering of family members is of equal and foundational concern. Numerous ChiPPS E-Journal issues focus on family and grief-related concerns.

When I read the articles in the ChiPPS E-Journal I see the faces of valued colleagues and continue to learn from them, as well as from the growing group of leaders across the country and internationally. I feel sustained by their broadening knowledge and continuing efforts. When I read the work of the expanding network of contributors who are carrying forward the deep commitment to children and their families, I feel inspired, reassured, and comforted. In spite of the immeasurable toll of illnesses, conditions, and treatments that limit children’s lives and cause distress, there are people who are devoted to offering excellent and compassionate care.

For all who are doing this work, for all the children and families, I send my deep gratitude and my admiration. Perhaps the most important part of life is to do what good we can, spreading hope and comfort. In quiet ways, with unseen ripple effects, we help children and families through their difficult experiences. The gifts we receive are life changing. We carry them with us always.

Congratulations and great appreciation to all involved in making the ChiPPS E-Journal such a living representation of all that is part of Pediatric Palliative and Hospice Care.

## **THE CHIPPS E-JOURNAL**

*Charles A. Corr, PhD*

Senior Editor

St. Pete Beach, FL

[ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com)

### **The Origins Of ChiPPs And The Chipps Conclave**

ChiPPS (originally, Children’s International Project on Pediatric Palliative/Hospice Services) grew out of discussions in 1995 among several practitioners in pediatric palliative and hospice care (PPHC) who faced challenges in their work resulting from relative isolation, limited research availability, and a lack of adequate resources to offer optimal care and services. As later described in the first ChiPPS E-Newsletter issue: “The group identified a need to disseminate current information about the care of children with life-limiting conditions in order to optimize the provision of comprehensive services that families need.”

Shortly thereafter, a multidisciplinary, multinational steering committee was established. In December 1996, the National Hospice Organization was approached and, with the support of Galen Miller, agreed to sponsor the project. In spring of 1997, Marcia Lattanzi-Licht agreed to become a consultant to the project who would facilitate, plan, and guide its development and also help organize preparations for a meeting that would bring together interested parties in the field. The two-day ChiPPS Conclave that was held in Texas in fall of 1998 gathered together an invited group of 35 international experts dedicated to the care of children with life-threatening conditions. At the Conclave, members identified critical questions and specific challenges in the field, and developed strategies to address selected issues. Multidisciplinary workgroups were formed to work on those issues.

ChiPPS activities directly following the Conclave are described in the inaugural issue of the ChiPPS E-Newsletter. As examples, they included: publication of a *Compendium of Pediatric Palliative/Hospice Care* (December, 2000); a day-long pre-conference institute as part of the 2nd Annual Joint Clinical Conference on Hospice and Palliative Care in Orlando, FL (March, 2001); a white paper entitled *A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions* (October, 2001); the development of an *Education and Training Curriculum for Pediatric Palliative Care* (published in 2003); and the promotion of the first conference focused entirely on pediatric palliative/hospice care held in Detroit in 2004..

### **The ChiPPs E-Newsletter: First Series**

The First Series of what was then called the ChiPPS E-Newsletter were essentially reports to interested parties by Dr. Betty Davies. The series began with an issue in December of 2002 in which she introduced ChiPPS, its activities, and its goals. She described this issue as an effort to begin "a regular communication to share information about recent developments, programs, activities, and events pertaining to palliative and hospice care for children" and went on to review the history of ChiPPS, its accomplishments, and its current activities.

The series continued with issues in March and May of 2003 that introduced the membership of the ChiPPS Executive Committee, described collaboration in efforts to develop The National Alliance for Children with Life-Threatening Conditions (NACWLTC), and reported the results of an NHPCO member survey on pediatric palliative care. An additional issue in July set forth a definition and principles of pediatric palliative care.

In 2004, an issue in January reported some recent activities in the field of pediatric care, including an invitation to join the new ChiPPS Education Workgroup, plans for a manual on how to start a pediatric palliative care program, and some legislative activities. Finally, an issue in May highlighted two conferences and some recent publications in the field.

### **The ChiPPs E-Newsletter: Second Series**

In October, 2004, the first issue of a newly revised, reformatted, and renumbered series of ChiPPS E-Newsletters appeared. Henceforth, this publication would be developed by the members of the ChiPPS Education Workgroup led by Dr. Stacy Orloff who, with Sue Huff, MSN, was now co-chair of ChiPPS. This and subsequent issues in the second series each had a distinctive theme (Issue #1 focused on pain), contained articles by multiple contributors, and provided additional information on activities and publications related to PPHC.

Two issues in the new series appeared in 2005 (focusing on bereavement and on sibling bereavement, respectively) and two more in 2006 (focusing on self-care and on teens coping with a life-threatening illness).

In 2006, Dr. Stacy Orloff relinquished her position as Chairperson of the Education Workgroup (although she continued at that time as Chairperson of the ChiPPS Advisory Council). In her place, Christy Torkildson and Charles Corr took over responsibility for the Education Workgroup and the ChiPPS E-Newsletter. In November of 2013, Chuck moved sideways to become Senior Editor for the E-Newsletter, but Christy has continued as Chair of the Workgroup (and managed to complete her doctorate alongside work, family, ChiPPS, and other responsibilities). From August 2007 (Issue #8), Mary Kay Tyler, RN, MSN, CNP, served as Co-Chair of the Education Workgroup for two years, followed by Maureen Horgan, LICSW, from August 2009 through November 2014 (Issues ##16 through 37).

In 2007, Issue #6 in the new series inaugurated what has now become a standard pattern of four issues per year, appearing quarterly in February, May, August, and November. Topics have ranged widely from perinatal and neonatal loss to perspectives of fathers and other males, to spirituality and families experiencing transitions, to complementary therapies, memory making, and legacy building. Other issues addressed stress and moral distress, education and training, and volunteers, as well as social media, the schools, and pain and symptom management. (See the attached list of all issues up to this point.)

In each issue, we strive to include submissions that are multi-disciplinary in nature. Also, we make an effort to include articles that represent family voices of those who are served in the field of pediatric palliative and hospice care in order to ground us in why we do this work.

In February 2014 (Issue #34), the name of this publication was changed from that of the ChiPPS E-Newsletter to the ChiPPS E-Journal to better reflect its nature and scope. Its organizing group is now called the ChiPPS E-Journal Workgroup.

As can be imagined, many of these topics addressed in each issue identify large subject areas. Sometimes, with an unexpectedly large number of contributions in hand, the Workgroup chose to split them into two successive issues. After discussions about this practice in May of 2016, however, it was decided not to do so in the future since devoting two issues to a single subject limits the range of subjects that can be addressed in a publication that only appears four times per year. Instead, it was thought better to confine each issue to a single subject area, while acknowledging that having only one issue on complex subjects can do little more than initiate and contribute to discussions on the topic it addresses.

Currently, there are over 3,300 subscribers to the ChiPPS E-Journal.

### **The ChiPPS E-Journal: Past And Future**

When an issue of the ChiPPS E-Journal becomes available, NHPCO announces that fact to its list of subscribers and invites them to log on to read that publication and all previous issues, which are available to subscribers and nonsubscribers alike at [www.NHPCO.org/pediatrics](http://www.NHPCO.org/pediatrics).

At the same time, on behalf of the Education Workgroup, we write to all contributors to the new issue to thank them for sharing their experiences and insights with us and our readers. In so doing, we always acknowledge that we could not continue to develop and publish this quarterly, electronic journal without their contributions. So we encourage them and all others, as we are now doing here, to continue to offer articles for the ChiPPS E-Journal, and we invite them to recommend other potential contributors, topics for articles, and subjects for issues.

Members of the ChiPPS Education Workgroup occasionally contribute articles to issues, but their main responsibility is to plan and select subjects for future issues, identify and invite potential contributors, and work with contributors to develop articles that will be interesting and useful for readers.

Everyone reading this article should know that they can join in this collaborative project, one which has now continued from its earliest beginnings in 2002. By joining the efforts of the ChiPPS E-Journal Workgroup, individuals can help define the future of this ongoing service and enrich what it has to offer to the community of professionals, volunteers, and family members who are involved in pediatric palliative and hospice care.

## **HISTORY OF CHIPPS E-JOURNAL**

### **FIRST SERIES**

<b>Issue#</b>	<b>Date</b>	<b>Subjects</b>
1	12/02	Beginning as ChiPPS E-Newsletter - introduces ChiPPS, its activities, and goals
2	3/03	Introduces half of the membership of ChiPPS Executive Committee and a collaboration to develop The National Alliance for Children with Life-Threatening Conditions (NACWLTC)
3	5/03	Introduces remainder of members of ChiPPS Executive Committee and reports results of an NHPCO member survey on pediatric palliative care

4	7/03	States definition and principles of pediatric palliative care
5	1/04	Reports some recent activities in the field of pediatric care, e.g., establishment of the ChiPPS Education Work Group, new resources, and legislative activities
6	5/04	Highlights two conferences and recent publications

**SECOND SERIES, REVISED, REFORMATTED, AND RE-NUMBERED**

<b>Issue#</b>	<b>Date</b>	<b>Subjects</b>
1	10/04	General
2	3/05	Bereavement
3	8/05	Sibling Bereavement
4	3/06	Self Care
5	9/06	Teens Coping with a Life-Threatening Illness
6	2/07	Perinatal Loss
7	5/07	Perinatal Loss (continued)
8	8/07	Neonatal Loss
9	11/07	Perspectives of Fathers and Other Males
10	2/08	Spirituality and Pediatric Palliative Care
11	5/08	Spirituality and Pediatric Palliative Care (continued)
12	8/08	Unsung Heroes in the Circle of Care
13	11/08	Pain and Pain Management in Pediatric Palliative Care
14	2/09	Pain and Pain Management in Pediatric Palliative Care (continued)
15	5/09	Families Experiencing Transitions
16	8/09	Overcoming Barriers to Pediatric Palliative Care
17	11/09	Complementary Therapies in Pediatric Palliative Care, Part One
18	2/10	Complementary Therapies in Pediatric Palliative Care, Part Two
19	5/10	Pediatric Hospice and Palliative Care in the United States: The Current State of the Art
20	8/10	Memory Making and Legacy Building in Pediatric Palliative and Hospice Care
21	11/10	Global Perspectives on Pediatric Palliative and Hospice Care
22	2/11	Ethical Issues in Pediatric Palliative and Hospice Care
23	5/11	Help and Healing: Bereavement Perspectives
24	8/11	Stress and Moral Distress: Identifying Stressors and Supporting Staff
25	11/11	Education, Training, and Resources for Pediatric Palliative and Hospice Care
26	2/12	Social Media and Electronic Communications: Networking by Families and Practitioners
27	5/12	What about Schools? Creating Systems to Support Children, Families, and Communities
28	8/12	Children are Not Little Adults: Some Differences in Providing Palliative Care
29	11/12	Stand Up and Be Counted: Honoring Volunteer Perspectives in Pediatric Palliative and Hospice Care
30	2/13	Perinatal Palliative and Hospice Care
31	5/13	Understanding and Helping Fathers and Other Males
32	8/13	Differences between Pediatric Palliative and Pediatric Hospice Care
33	11/13	The Affordable Care Act and Concurrent Care for Children
34	2/14	Renamed the ChiPPS E-Journal Transitions in Pediatric Palliative and Hospice care
35	5/14	Selected Issues near, at, or Following the Death of a Child
36	8/14	Children with Medical Complexities, Part One
37	11/14	Children with Medical Complexities, Part Two
38	2/15	Advance Planning in Pediatric Hospice/Palliative Care, Part One
39	5/15	Advance Planning in Pediatric Hospice/Palliative Care, Part Two

40	8/15	Establishing and Providing Pediatric Palliative/Hospice Care in Different Settings or in Different ways, Part One
41	11/15	Establishing and Providing Pediatric Palliative/Hospice Care in Different Settings or in Different ways, Part Two
42	2/16	Bereavement and Care, Part One
43	5/16	Bereavement and Care, Part Two
44	8/16	Communicating with Children and Parents
45	11/16	Pain Management with Children
46	2/17	Symptom Management with Children
47	5/17	Care of Siblings and Grandparents
48	8/17	Spiritual Support of Families and Children
49	11/17	Perinatal and Neonatal Care
50	2/18	Celebrating the Past and the Future of Pediatric Palliative/Hospice Care, ChiPPS, and the ChiPPS E-Journal

## A PERSONAL PERSPECTIVE OF PALLIATIVE CARE FOR CHILDREN FROM THE UK

**Ann Goldman, MA, MB, BChir, FRCPCH**

Paediatrician, (now retired)

The Hospital for Sick Children

Great Ormond Street London

[ann.goldman1@gmail.com](mailto:ann.goldman1@gmail.com)

### Setting the Scene for Palliative Care for Children

As a keen gardener I know that when the soil is fertile many seeds will germinate and grow. In the late 1970s and early 1980s the changes that had been happening in society and medicine acted as the fertile soil for the seeds of a number of palliative care projects for children to grow.

Expectations of health care were changing. With greater prosperity, higher standards of care were demanded and patients were wanting less deferential relationships with clinicians. Personal autonomy was becoming more important and patients were looking for partnership and choices in care for themselves and their children.

Society was becoming more open, women's roles were stronger, and children's voices were beginning to be heard. Even the silence and taboos around cancer and death were being challenged. Kübler Ross had written *On Death and Dying*, Bluebond Langner told us about *The Private Worlds of Dying Children*, and Sahler wrote about *The Child and Death*.

There were relevant changes in medicine, too. The patterns of illness were altering, with a decrease in acute and infectious illness, and therefore an increase in the relative importance of chronic illness. This changed the profile of children in hospital. The idea of holistic care with emphasis on whole person was emerging as a reaction and counter balance to the increased technology in medicine.

The model of palliative care in adults had been established by their pioneers; Cicely Saunders at St Christopher's Hospice in London, Balfour Mount's hospital-based palliative care unit in Montreal, and The Connecticut Hospice with Florence Wald.

With this fertile background the early shoots of palliative care for children appeared, at around the same time, in different places. My role as a paediatrician specialising in palliative care and the Symptom Care Team at Great Ormond Street Hospital were among these first projects.

### My Journey

My background was in paediatrics and paediatric oncology. Several years in a laboratory with mice and monoclonal antibodies convinced me that I was better suited to clinical care. However, the research also brought me into close contact with many children with advanced neuroblastoma and their families who were part of the trial of our radiolabelled monoclonal antibody. All

these children subsequently died and I became aware of how intensely oncology resources and research were focussed on improving prognosis. Although oncologists continued to care for the children who relapsed and were dying, no one was intensely focussed or researching their symptom management and care needs. This was a gap which I decided to fill and with the support of my senior colleagues and funding from a charity. I drew up my own new job description as a paediatrician with special interest in palliative care and established the symptom care team. We were based in the haematology and oncology department at Great Ormond Street Hospital for Children in London and were the first multidisciplinary, hospital-based children's palliative care team. Although we were based in the hospital and cared for all members of the families, we also provided extended care, visiting children at home or in their local hospitals, and working with and supporting local care givers. Gradually, as I had always intended, we began to offer help to clinicians in other departments and care for children who had any life-limiting illness and their families.

### **Developing Children's Palliative Care Nationally**

Other pioneering services were being developed around the UK at this time; Helen House, the first children's hospice had opened, oncology nurse specialist teams and child and family bereavement projects were being established. As their number increased, I was pleased to be part of an important initiative to bring these groups together as well as with parents to establish an umbrella organisation to work on behalf of the needs of all children with life-limiting and life-threatening illnesses. This was ACT (the Association for the Care of Children with Life Limiting and Life Threatening Illnesses), now called Together for Short Lives, which has had a powerful role in lobbying to raise the profile and improve the care for the children and families and support and educate clinicians, throughout the UK. Through ACT we spread information about the groups of children who might benefit from palliative care and the need for it to encompass care from the time of diagnosis (in contrast to palliative care in adults), end-of-life care, and through to bereavement support for the family.

I am proud to have been part of this and now be a vice president. I am also proud to be able to have been able to establish a palliative care group within the Royal College of Paediatrics and Child Health, to have established the first training post for paediatricians, and to be one of the editors of *The Oxford Textbook of Palliative Care for Children*.

### **The Future**

Equal access to palliative care is a fundamental ideal for any child with a life threatening illness, whatever their age or diagnosis and wherever they live. There are still huge numbers of children and families who could benefit from palliative care but do not have access to it. Even in well resourced countries, although we have made great progress, the quality and availability of support is far from universal. The role for palliative care for neonates and in the PICU is still evolving. Unfortunately, many myths and misunderstandings about the philosophy and practice of palliative care still remain, both among the public and health care professionals.

The WHO (World Health Organisation) have identified that 98% of children needing palliative care live in low and middle income countries and the ICPCN (The International Children's Palliative Care Network) have looked at global provision and there are still large areas with high populations and no palliative care for children. There also remains a huge discrepancy in the access to opioids and other medications for those children and young adults who need them, between North America, Western Europe, and the rest of the world.

I believe that one of our most important roles for the future is for palliative care for children to be recognized as a beacon of good clinical practice and humane care. We have a powerful opportunity to use and teach the ethos and principles of palliative care and through this we can help improve care for children and families around the world.

## ADVANCE PLANNING IN PEDIATRIC CARE

*Blyth Lord, EdM*

Executive Director

Courageous Parents Network

[blord@courageousparentsnetwork.org](mailto:blord@courageousparentsnetwork.org)

This past fall, Courageous Parents Network fielded a survey of parents who had used our services—videos, blog, podcasts, Facebook Live events, and related content—during their child’s life and/or after becoming bereaved. Our goal was to learn about a number of things, most especially what parents identify as their top priorities for which they would seek help.

We had a generous number of completed surveys and here is what we learned: All parents, regardless of whether their ill children are still living or are deceased, want to be the best parents they can possibly be. Accordingly, they placed the highest value on having the ability to\*...

1. Advocate for their child’s needs
2. Make decisions that work with their family’s values and goals
3. Set priorities that feel right for them and their child
4. Dedicate attention to their other children

\*Note: The survey did not include questions about pain and symptom management so findings could not include ‘keeping my child physically comfortable or free from suffering.’

These findings are generally consistent with what larger surveys of parents of seriously-ill children have found. They echo what our conversations are like around the Courageous Parents Network “kitchen table” when our staff and parent advisory board start talking about our experiences. And, they certainly resonate with me personally when I remember what mattered most to my husband and me as we adapted to our daughter’s fatal diagnosis and managed her care and transition to end-of-life.

With the exception of the fourth item, these findings fall under the umbrella of advance care planning. **And the good news, the really good news from where I sit as a parent advocate for pediatric palliative care, is that the articulated need as seen in our data corroborates the sense that growing awareness of and demand for advance care planning can move palliative care services into prime time—out of the small circle of specialists and into the larger circle of primary care and front-line providers who work with seriously-ill children.** Which means that we can realize our goal of having those vulnerable, sacred, and pivotal conversations be less dependent on whether the child and family has a palliative care specialist on the team.

What is the evidence for this?

Most of you know of Dr. Atul Gawande’s beautifully articulated vision in *Being Mortal* for how the medical profession must shift its focus from extending life to helping people have the best days possible. **Well-being over Being.** He has his hands in several initiatives based in Massachusetts, where I live and where Courageous Parents Network is based, that give me real hope as beacons of light and signs of things to come.

First, there is the Massachusetts Coalition for Serious Illness Care. Founded in 2016, this is a coalition of physicians, nurses, hospice workers, counselors, clergy, hospital and health plan administrators, social workers, attorneys, policymakers, researchers, and other health professionals dedicated to ensuring that health care for everyone in the state is in accordance with their goals, values, and preferences. Its founding members are Gawande (Ariadne Labs), Ellen Goodman (The Conversation Project), Andrew Dreyfus (CEO of BCBS of MA), and Maureen Bisognano (Senior Fellow at the Institute for Healthcare Improvement). These are non-specialists who want to bring training in the fundamentals of advance care planning, such as care goals and wishes and communication, to **everyone and anyone** who works with the seriously ill, from pre-natal to geriatrics. This year, the Coalition successfully advocated with Massachusetts’ four medical schools, which have now jointly agreed to

teach students and residents how to talk with patients (and caregivers) about what they want from life; thus, future doctors will know how to help families navigate decision making. I am cautiously optimistic that Massachusetts is a bellwether for things to come across the country.

Another of Dr. Gawande's initiatives is the Serious Illness Care Program at Ariadne Labs, with its Serious Illness Conversation Guide to training non-palliative care specialists in advance care planning with patients (developed with Dr. Susan Block). The program seems to be focused entirely on adult patients. What gives me such hope in this moment, on this topic, is that pediatric providers are independently adapting it for use and training with primary care pediatricians.

For example, with assistance from several palliative care specialists, Dr. Christine Bennett (InterMed, Portland, Maine) has adapted the Serious Illness Conversation Guide into a training for primary care pediatrics called Discussions about Serious Illness (DASI). This fall, I was fortunate to participate in the second round of DASI training of primary care pediatricians at a large medical practice. Part of the training involves the pediatricians' role-playing "the conversation" with a parent. In the debrief that followed, several of the pediatricians commented that they saw how well-suited they already are to talking with families about their care goals and values and about what they want for their child. I am cautiously optimistic that they will be bringing this realization and new confidence back to their practice. This is the work **our daughter's** primary care pediatrician did with us and it made all the difference in the world. May it be so for other families.

Then, in December, Massachusetts General Hospital for Children hosted its Primary Care Pediatrics conference. Dr. Patricia O'Malley (Director, Pedi Pall at MGHforChildren and member of the Courageous Parents Network Advisory Board) and I presented on advance care planning and palliative care in primary care in a session titled, "We should talk." Our session couldn't compete in numbers with the concurrent session on endocrine issues, but the smaller group of attendees from around the world were there to learn how they could practice the fundamentals of good communication, anticipatory guidance, and goal setting with families of the few seriously-ill children in their practice. These practitioners didn't just want to stay involved in the child's care, they wanted to share a leadership role with the specialists who were focused on the disease and symptom management.

One of the attending pediatricians shared his challenge of a particular family: The baby was recently diagnosed with a condition that is still always and absolutely fatal in early childhood, but the parents will talk only about their hope for his recovery and survival. Dr. O'Malley talked about framing the conversation as that delicate balance between Wishes and Worries: "I too wish for a miracle and I worry about what happens if we don't get that miracle. Can we talk about what you wish for if that miracle doesn't happen?" The pediatrician nodded as he took in what she was saying. I am cautiously optimistic that the hour these pediatricians spent with us will fuel their confidence and commitment to lead sometimes and accompany always the families in their care.

Meanwhile, Courageous Parents Network will do its part by celebrating those primary care pediatricians who do stay active in the child's care and who do practice palliative care fundamentals, including advance care planning. On Courageous Parents Network's website, we feature videos of parents talking about the role their child's primary care doctor played in their child's illness journey, the difference the doctor made. For example, the mother of a little girl with infantile Gaucher Type 2 puts her daughter's PCP pediatrician front and center: "We were lucky our pediatrician became just our point person for everything. She provided stability and was someone we could trust. She's not a palliative care specialist, but primary care. But she's really into it. She anticipated things we might need before we did. She was the key that held everything together for us because from the point of diagnosis to the point of Emerson's death, she was involved."

In another video, the mother of a child with leukodystrophy notes that it is her child's pediatrician who "nudges us and asks, 'Are you sure you want to do these things that won't help her quality of life?'"

And the mother of a teenager with Canavan disease notes that it is her daughter's pediatrician who initiated the conversation about medical orders and helped her draft the DNR. She said, "It's tough to talk about end of life issues and preparedness, but it's part of what we have to go through."

My dream for the families of seriously-ill children and for the field of palliative and hospice care is, of course, that there is a bountiful supply of trained palliative care specialists to meet the needs of every child and family and that they are compensated accordingly. In the meantime, I find hope and promise and goodness in the move to bring advance care planning awareness and skills to those front-line pediatricians who know the whole family best.

## **EDUCATION: THE KEY TO PROVIDING, MAINTAINING, AND SUSTAINING EXCELLENT PEDIATRIC PALLIATIVE CARE**

***Pam Malloy, MN, RN, FPCN, FAAN***

**ELNEC Co-Investigator**

**Special Advisor on Global Initiatives**

**American Association of Colleges of Nursing (AACN)**

**Washington, DC**

**[PMalloy@aacnnursing.org](mailto:PMalloy@aacnnursing.org)**

***Cheryl Thaxton, MN, RN, CPNP, FNP-BC, CHPPN***

**Advanced Practice Registered Nurse**

**Palliative Care Team**

**University of Texas Southwestern Medical Center**

**Dallas, TX**

**[thaxca@aol.com](mailto:thaxca@aol.com)**

***Vanessa Battista, RN, MS, CPNP***

**Pediatric Nurse Practitioner**

**Pediatric Advanced Care Team**

**The Children's Hospital of Philadelphia**

**Philadelphia, PA**

**[BattistaV@email.chop.edu](mailto:BattistaV@email.chop.edu)**

***Betty Ferrell, PhD, RN, MA, CHPN, FPCN, FAAN***

**Professor, Director of Research and Education**

**Principal Investigator of ELNEC**

**City of Hope**

**Duarte, CA**

**[BFerrell@coh.org](mailto:BFerrell@coh.org)**

### **Overview**

It would be impossible for pediatric palliative care (PPC) providers working with very sick and/or dying children and adolescents (herein referred to as “children”) not to experience the emotional toll that comes from this work. At times, it feels as if there are far more sick children than those that are well. It is thus encouraging to know that according to the Centers for Disease Control and Prevention (CDC), 85% of children in the U.S., from the ages of 5-11 years are in very good/excellent health and 95% of those 18 years and younger have access to health insurance (CDC, 2015). Because the prevalence of children in the U.S. living with life-threatening or chronic illness (i.e., congenital and chromosomal abnormalities, nervous system diseases, cancer) is estimated at 400,000 or higher (CAPC, 2016), it is necessary that nurses continue their education in preparing to care for this unique population suffering with complex illness/injuries and their families. Each year, more than 63,000 children die; greater than 23,000 of them are infants and approximately 42,000 of these children are less than 19 years of age (CDC, 2015). Recent CDC statistics show that U.S. fetal mortality rates were 6.05 per 1,000 live births (CDC, 2015), and 9,080 children from the ages of 1-14 years died, with the most common causes being unintentional injuries, heart defects, cancer, assault, and intentional self-harm (CDC, 2017).

### The Growth of Pediatric Palliative Care (PPC) Programs

The World Health Organization (2017) defines pediatric palliative care as:

- Active and total care of the child's body, mind, and spirit, while giving support to the family.
- Begins at the time of diagnosis of a serious illness and can continue in tandem with active treatment.
- Provides holistic care—assesses and manages not only the child's physical pain, but also psychological and social suffering.
- Utilizes multidisciplinary staff, including meeting the needs of the family and using appropriate community resources.
- Implemented in tertiary care facilities, in community health centers, and even in children's homes.

PPC programs have continued to expand throughout the U.S. to provide vital resources for children and families. Nurses must be educated in order to provide the care needed to provide patient-focused, family-centered care, incorporating pain and symptom management, and providing information and promoting implementation of seamless care (Thaxton et al., 2015). Children who require medical care through inpatient and outpatient PPC programs receive complex care for issues such as pain, dyspnea, anxiety, nausea, vomiting, diarrhea, depression, delirium, fatigue, and other distressing symptoms. Nurses depend on continuing education to prepare them for advocating in decision-making, establishing goals of care, and caring for members of the child's family and community.

Nurses working in outpatient facilities are receiving further education, as these settings are expanding palliative care in complex chronic care (CCC) clinics for children with life-limiting illnesses, which in turn supports the neonatal, pediatric, and adolescent population while addressing disease-specific needs (neuromuscular, pulmonary, neurology, cardiac, etc.). Healthcare providers value the unwavering services extended by PPC teams because the programs help to transform situational distress into care that is individualized and better coordinated. The goal of improving children's quality of life remains the core focus of PPC. Because meeting this goal is so vital, work must continue until every child with a serious life-threatening illness/injury and his or her family has access to palliative care. While people are actively advocating for this care, nurses are on the forefront to make sure the healthcare providers are educated and prepared to meet the unique needs of the most vulnerable in our society.

### Responding to the Need: END-OF-LIFE NURSING EDUCATION CONSORTIUM—Pediatric Palliative Care (ELNEC-PPC)

Nurses who spend more time at the bedside or in the community than any other healthcare professional play a significant role in facilitating effective collaboration among the interdisciplinary team to ensure that goals of care are met in a wide variety of pediatric clinical settings. To make care seamless in both inpatient and outpatient clinical settings, nurses must assume the role of care provider, advocate, and educator. However, all of this sacred work starts with education, as nurses cannot practice what they do not know.

In response to meeting nurses' needs in palliative care education and training, the ELNEC project began in 2000 as a partnership between the City of Hope and the American Association of Colleges of Nursing (AACN) to advance palliative care nursing. Funds were received from the Robert Wood Johnson Foundation to develop a palliative care curriculum specifically for nurses, ELNEC-Core. While ELNEC-Core was a much-needed and adult-focused curriculum, it did not address the specific and unique needs of children and their families. In 2003, ELNEC-PPC debuted in Pasadena, CA with 110 pediatric nurses from across the U.S. in attendance. Today, over 2,500 pediatric nurses and other healthcare providers have attended a national train-the-trainer course and have returned to their institutions to educate over 65,000 nurses and other interdisciplinary team members about this care. In 2009, the curriculum was updated to include enhanced perinatal and neonatal content and in 2014 a specific curriculum was developed to meet the unique needs of those in advanced practice, ELNEC-PPC-APRN. Modules developed for both ELNEC-PPC and ELNEC-PPC-APRN provide not only didactic content, but also opportunities to review case studies, to view communication vignettes, and to role-play various practice scenarios (Table 1).

Nurses have reported that receiving palliative care education makes them feel inspired and privileged to assist children and families during such a difficult time (Battista & LaRagione, 2015). Nurses who have attended a national ELNEC-PPC train-the-trainer course return to their institutions and plan and provide this care in unique ways. To date, ELNEC-PPC has been taught throughout Eastern Europe and has been translated into the Japanese, Korean, and Chinese languages.

## Translating Education into Practice

Throughout the United States, there are examples of exceptional nurses who have created model PPC programs. They have taken the knowledge they have learned through educational programs such as ELNEC and translated it into practice and they, in turn, have created educational programs to expand the knowledge base for their colleagues, both fellow nurses and other clinicians. For the purposes of this article, only two such programs will be highlighted, but several programs exist that exemplify the ways in which nurses truly serve as leaders in the field of PPC.

One extraordinary example of strategic implementation of primary pediatric palliative care is the work that Deborah LaFond, DNP, PPCNP-BC, CPON, CHPPN, has established through the PANDA Care Team at Children's National Health System (CNHS) in Washington, D.C. The program, established in 2005, is nurse-driven and focuses educational efforts on preventing, reducing, and soothing symptoms of patients in the advanced stages of illness. In 2015, Dr. LaFond was chosen as a Cambia Health Foundation Sojourns Scholar and received a \$1.8 million grant to advance her work in pediatric interprofessional care. This grant has allowed Dr. LaFond to establish a specialty palliative care program, the PANDA Cubs program, an intensive educational and mentoring program aimed at preparing direct-care clinicians from all disciplines in basic palliative care. The PANDA Cubs program, which began in 2016, is based upon ELNEC-PPC and Education in Palliative and End of Life Care-Pediatrics (EPEC-Peds) curricula. Over 145 professionals (physicians, advanced practice nurses, RNs, social workers, child life specialists, chaplains, patient care technicians, volunteer coordinators, and community hospice partners) have participated in the PANDA Cubs program thus far. The program consists of a 2-day didactic conference, quarterly education seminars, monthly team mentoring, and concludes with a 1-day workshop. Throughout the year-long program, the participants work on a quality improvement project to establish meaning and bring the knowledge, skills, and attitudes regarding palliative care back to their units with the goal of impacting patient/family outcomes and/or staff support. Outcomes of this program have included an increase in palliative care consults by specialty practitioners, clinician self-report of improvements in providing palliative care, and the establishment of palliative care as a standard of care in several disease-specific specialty areas. The PANDA Cubs program has been very successful and further cohorts are planned to include community primary care providers. For more information on this project, go to <https://childrensnational.org/choose-childrens/deciding-on-care/support-for-families/panda>.

Another example of nurse-led expansion of pediatric palliative care in the community is the development of Hands of Hope®, the pediatric division of Hospice Care of South Carolina, established by Diane Parker, RN, MSN, NE-BC, CHPN, CHPPN. Hands of Hope is the only comprehensive interdisciplinary pediatric resource team to provide pediatric hospice and palliative care in South Carolina (NHPCO, 2017). Hands of Hope consists of an interdisciplinary team of specialists in pediatric care including nurses, medical social workers and chaplains, child life specialists, and bereavement coordinators who provide comprehensive palliative and comfort care to children and families (Hands of Hope, 2017). ELNEC-PPC provided the education and training for this program and it serves as a foundation for their work. Ms. Parker revolutionized care for children and families living with life-limiting and life-threatening illnesses throughout the state of South Carolina by serving as the catalyst for change in the regulatory and legislative landscape of pediatric care. For more information on this project, go to <http://www.handsofhopesc.net/>.

Both Ms. Parker and Dr. LaFond serve as nurse leaders in the field of PPC, as they expand their knowledge of PPC to educate other clinicians and to increase the breadth and depth of PPC that children and families receive.

## Conclusion

The future of PPC is rapidly expanding, and nurses are an integral and crucial part of this expansion. There is not a more frightening episode for a child than for him/her to become seriously ill. There is not a more difficult time for parents than witnessing their child become seriously ill. Nurses have the opportunity and the privilege to provide care and presence during this vulnerable time. Thus, nurses can and must continue to seek ways to learn more about how to better serve the needs of the many precious children and families who can benefit from comprehensive and effective PPC.

For more information on attending a national ELNEC-PPC train-the-trainer course, go to [www.aacnnursing.org/ELNEC](http://www.aacnnursing.org/ELNEC). For information about how to access ELNEC-PPC on-line, for training purposes only, go to <https://www.reliaslearning.com/elneec>.

**Table 1: ELNEC-PPC and ELNECPPC-APRN Modules**

ELNEC-PPC	ELNEC-APRN PPC
Introduction to Pediatric Palliative Nursing	Introduction to Pediatric Palliative Nursing
Pain	Pain
Symptom Management	Symptom Management
Communication	Communication Lab
Loss, Grief, Bereavement	Opportunities for “Generalists” and “Specialists”
Cultural Considerations	Final Hours
Ethical Implications in Palliative Care	
Perinatal and Neonatal Palliative Care	
<b>Small Group Labs</b> <ul style="list-style-type: none"> <li>■ Review of Case Studies</li> <li>■ Self-care</li> <li>■ Role play</li> </ul>	Small Group Labs: <ul style="list-style-type: none"> <li>■ Communication Lab #1: Breaking Bad News/Family Meetings</li> <li>■ Communication Lab #2: Speaking with a Physician Who is Resistant About a Palliative Care Consult</li> <li>■ Review Equianalgesia Calculations</li> <li>■ Building and Maintaining Pediatric Palliative Care Programs</li> </ul>

**References**

Battista, V., & LaRgione, G. (2015). Pediatric hospice and palliative care (Chapter 56). *The Oxford Textbook of Palliative Nursing* (pp. 851-872). In BR Ferrell, N Coyle, & JA Paice (Eds). New York, NY: Oxford Publishing.

Centers for Disease Control and Prevention (CDC). (2017). Child Health. <https://www.cdc.gov/nchs/fastats/child-health.htm> .

Centers for Disease Control and Prevention (CDC). (2015). Trends in Fetal and Perinatal Mortality in the United States, 2006–2012.

Center to Advance Palliative Care (CAPC). (2016). Pediatric palliative care field guide: A catalogue of resources, tools and training to promote innovation, development and growth. [https://media.capc.org/filer\\_public/58/70/587067d2-ba65-4263-a29e-25dca6b2e0df/peds\\_pc\\_field\\_guide\\_111116.pdf](https://media.capc.org/filer_public/58/70/587067d2-ba65-4263-a29e-25dca6b2e0df/peds_pc_field_guide_111116.pdf).

Hands of Hope. (2017). About Us. <http://www.handsofhopesc.net/about-us>.

National Hospice and Palliative Care Organization (NHPCO). (2017). <http://nhpco.confex.com/nhpco/MLC15/webprogram/Person75026.html>.

Thaxton, C, Carter, B, & Hornik, CD. (2015). Palliative care in the neonatal intensive care unit (Chapter 59). *The Oxford Textbook of Palliative Nursing* (pp. 909-924). In BR Ferrell, N Coyle, & JA Paice (Eds). New York, NY: Oxford Publishing.

World Health Organization (WHO). (2017). WHO Definition of Palliative Care. <http://www.who.int/cancer/palliative/definition/en/>.

## THE FUTURE OF PEDIATRIC HOSPICE AND PALLIATIVE CARE

*Rachel Thienprayoon, MD, MSCS, FAAP, FAAHPM*

**Assistant Professor of Anesthesia and Pediatrics**

**Medical Director, StarShine Hospice**

**Cincinnati Children's Hospital**

**Cincinnati, OH**

[Rachel.Thienprayoon@cchmc.org](mailto:Rachel.Thienprayoon@cchmc.org)

In 2012, as I developed my application for a fellowship position in palliative medicine, only 7 dedicated pediatric fellowship positions were available at 5 programs across the United States. According to the AAHPM, in 2017 our field boasts 19 dedicated pediatric palliative medicine fellowship programs, many of which offer two positions, and an additional 16 adult programs that offer “pediatric tracks.” This increasing availability of fellowship training opportunities illustrates the profound evolution of our field over the past two decades. As the rate of change accelerates, and acceptance of palliative care yields to systemic commitment, we should anticipate myriad innovative and vibrant possibilities for the future of pediatric hospice and palliative care.

With the advent of advancing technologies and gene therapies, diseases that were once uniformly fatal are being transformed into chronic illnesses of childhood and young adulthood. Infants born with cystic fibrosis, Duchenne muscular dystrophy, and spinal muscular atrophy now represent unique populations from those born in my generation. As their families navigate uncertain futures, and physician scientists strive to cure the as yet incurable, the need for subspecialty pediatric palliative care will continue to outpace our ability to train providers. We will be called upon to ensure that general pediatricians and other subspecialists are capable of providing basic, primary palliative care. Subspecialty-trained pediatric hospice and palliative care providers will thus be unencumbered to focus on secondary and tertiary palliative care needs: management of refractory symptoms, navigating difficult discussions about goals of care, and assisting with complex medical decision making.

Perinatal hospice and palliative care is an important frontier in pediatric palliative care. Comprehensive perinatal hospice and palliative care, provided across settings, should become the standard for both women who carry, as well as for those who terminate, a pregnancy which is likely to result in death of the infant. We increasingly appreciate that outcomes for some of these infants are also uncertain, and perhaps brighter, than previously believed. As we know from Kate Nelson's work, a cohort of infants with Trisomy 13 and Trisomy 18 will live for several months to years. Fetal care centers will increasingly offer cutting edge therapies to infants with diagnoses which were previously believed to be universally fatal. The seamless integration of pediatric palliative care providers into the care of these families is crucial to again help navigate the complexity of decision making, to advocate for the family's wishes, and to allow for meaningful legacy work for all family members both during the pregnancy and after birth.

Finally, over the coming years it will be critical that research and quality improvement efforts not only grow, but remain tightly wed, bearing fruit in the form of measurable, evidence-based outcomes and benchmarks across programs and settings. Pediatric palliative care and pediatric hospice care are distinct entities from adult hospice and palliative care. We have a responsibility to provide care—in the hospital, in the home, and in the community—that is rooted in science and resulted from studies specific to our patients. Pediatric palliative care fellows should be expected to understand clinical research methods, and should have opportunities to pursue additional training in clinical research. Likewise, the consistent, standardized application of such evidence will require knowledge of quality improvement methods, necessitating ongoing QI training opportunities. Collaborative efforts in our field will become the norm. Pediatric palliative care leaders will be expected to demonstrate that we provide care that is safe, effective, efficient and equitable, in addition to care that is patient- and family-centered (our favorite!).

The past five years of my career have been both inspirational and humbling. It is said that pediatric palliative care providers across the country envision ourselves as one large department. The comradery, affection, and energy in our field are palpable. We must continue to harness that energy and excitement, alongside our patients and their families, to drive our field forward together over the coming decades.

## ADVANCING THE FUTURE GROWTH OF PEDIATRIC HOSPICE AND PALLIATIVE CARE

*Conrad Williams MD, FAAP, FAAHPM*

Medical Director, Palliative Care Program

Assistant Professor, Department of Pediatrics

Medical University of South Carolina

Charleston, SC

[wilcon@musc.edu](mailto:wilcon@musc.edu)

I am frequently asked why I decided on pediatric hospice and palliative medicine as a career. One of the main reasons I often share is the tremendous potential for growth in the field. The opportunity for growth is present for both individuals and the specialty as a whole. As a very new specialty, pediatric hospice and palliative medicine is much like a teenager—energetic, eager to please, moody, naïve, feeling invincible, and not quite sure what adulthood will bring. The pioneers of pediatric hospice and palliative care remain in the prime of their careers and there is a growing number of young professionals eager to have a role in the maturation of the specialty. The exciting future is fraught with challenges; effective growth will come from deliberate efforts aimed at advancing the field. I will share here my thoughts on what the future holds for pediatric hospice and palliative care by focusing on four areas: clinical care, advocacy, research, and education.

Our interactions at the bedside with patients and families form the heart of hospice and palliative care. Our focus must be on providing advanced, consistent, and impactful clinical services across all healthcare settings. Programs across the country have developed based on the unique needs and environment of their home institution. As a result of this organic growth, there is wide variability in the breadth and depth of services available in different healthcare systems—“if you’ve seen one palliative care program, you’ve seen one program.” We need to work to define what pediatric hospice and palliative care should look like:

- What services should a specialty team provide (what are the reasons for a palliative care consult)?
- What core palliative care skills should every provider possess regardless of specialty (primary palliative care)?
- What are the essential components of a transdisciplinary program that all healthcare systems should have? If a health system commits to palliative care then the team must consist of a core set of interdisciplinary professionals.

National collaborative efforts centered on provision of high quality palliative care are beginning to develop. Individual programs must commit to these efforts to allow for development of robust clinical standards of care. Quality initiatives such as the [Palliative Care Quality Network](#) and the [Global Palliative Care Quality Alliance](#) offer the infrastructure to facilitate such efforts. While these both focus on the adult world, we should work closely with them to overcome barriers to participation such as cost, ease of data entry, and value of participation for pediatric programs. Furthermore, pediatric programs should commit to annual participation in the [National Palliative Care Registry](#) which will hopefully develop a pediatric specific registry in the near future.

This care should be provided in whatever location best suits the needs of the patient and family. In this evolving healthcare system, there is growing emphasis on quality and value of care with a focus on patient and family-centered care. Palliative care is positioned to flourish in the healthcare system by improving the patient experience of care and positively impacting health care costs. The future of palliative care is in growing past the walls of a hospital and out into the community. The use of telehealth to increase access to services will be crucial.

Advocacy efforts must also mature. I define advocacy very broadly, but I will first discuss legislative advocacy. National efforts should focus on protecting and expanding resources for pediatric healthcare in general—any threat to healthcare coverage for all children will disproportionately impact children with serious illnesses and their families. We must also ensure a strong pediatric voice in all hospice and palliative care national policy initiatives led by organizations such as the American Academy of Hospice and Palliative Medicine and the National Hospice and Palliative Care Organization. I believe that the most impactful legislative advocacy is likely to be on the state level. State advocacy is often less imposing and easier to initiate efforts. Furthermore, a large number of children are covered by Medicaid, the structure of which can vary significantly from state to state. Programs

that are in states with progressive Medicaid policies or initiatives supporting pediatric palliative care services should share these efforts to encourage those from other states to explore the possibility of adapting such policies. We should also work with the Center to Advance Palliative Care on such policy matters. CAPC has done significant work on advancing hospice and palliative care program development through policy and payment advocacy on both a national and state level. They have resources that would provide a strong foundation for such efforts focused on pediatrics.

Advocacy efforts should focus on empowering the other disciplines involved in palliative care to have a stronger voice in the field. I often feel that, as a physician, I am the least important part of a team at times with other disciplines taking the lead in providing needed services to patients and families. Increased opportunities for such disciplines to take leadership roles within programs and nationally will serve to strengthen the field in general.

We must also advocate for our own wellness to sustain this work. Individuals or programs with successful wellness efforts should share such initiatives. It is also important to sustain the energy of young career providers—encourage leadership development, promote clinical mentorship and foster wellness techniques.

There is also tremendous opportunity for growth in pediatric hospice and palliative care research. When establishing services, it is no longer sufficient to just discuss the general benefits of our services by pulling on heart strings and trying to convince outsiders that this is “the right thing to do.” We need to work to identify the specific impact that our services can have on specific patient populations and their families. The majority of the evidence around effectiveness focuses on the oncology population. While there remains great potential for further research in this area, oncologic diagnoses **probably aren’t the most common diagnostic category** for patients receiving palliative care services. (On a side note, the type of information available in the above linked cohort study by Feudtner, et al. is the type of information that we should know about palliative care across the country. Such information should be made easy for programs to share in a central location that would then paint a broad picture of what pediatric hospice and palliative care looks like in America.)

We need to identify the specific impacts that our services can have on specific patient populations, disease categories, and healthcare systems. It is through this research that we will mature as a field and reduce the persistent barriers to access. In addition, a **recent article** highlighted the potential existence of socioeconomic disparities in palliative care. It is imperative that the benefits of specialty palliative care services are distributed equitably.

We should collaborate with providers in other specialties to look at impact of our involvement. Furthermore, we should also consider sharing the results of such work at conferences and in journals of the collaborating specialty. I think the focus of national meetings such as the AAHPM Annual Assembly should be on the internal maturation of our specialty—fellowship standards, quality initiatives, leadership and mentorship development, and networking opportunities—while encouraging us to spread the “good news” of our services externally.

Finally, education is crucial to our future. In the two hospitals I have worked since leaving fellowship, I found that focused internal education efforts have led to tremendous growth in program volume. Specifically targeting education for bedside nurses and physician trainees can lead to culture changes in a unit or even an entire hospital resulting in increased specialty palliative care penetrance while improving the primary palliative care skills of these providers. It is also important to move palliative care education upstream—integrate the core concepts into the curriculum for students of all disciplines involved in caring for those with serious illness.

When I applied to fellowship in 2011, there were only three accredited programs. Since then that number has **grown to over 30**. While this is tremendous, it is important that we focus on ensuring the fellowship experience is uniform and that it also focuses on skills related to program development since many physicians enter positions of leadership directly out of fellowship. Finally, I would encourage programs to look for ways to educate the general public about palliative care. The benefits can be multiple—increased access, decreased misperceptions, recognition of program by leadership, and enhanced philanthropic support among others. Collaborating with local media partners can help to tell the powerful story of pediatric palliative care.

As our field looks to mature, it is imperative that we focus our efforts in the coming years on strengthening the specialty through dedicated and collaborative work on enhancing the clinical, advocacy, research, and educational efforts with the goal of increasing access to palliative care services across the country and beyond.

## EARLY INTEGRATION OF PEDIATRIC PALLIATIVE CARE INTO PEDIATRIC ONCOLOGY PRACTICE: THE TIME IS NOW

*Holly Spraker-Perlman, MD, MS*

*Angela Snyder, DNP*

*Justin N. Baker, MD*

Department of Oncology

Division of Quality of Life & Palliative Care

St. Jude Children's Research Hospital

Memphis, Tennessee

[holly.spraker-perlman@stjude.org](mailto:holly.spraker-perlman@stjude.org)

It is an exciting time to be a pediatric oncology AND pediatric palliative care (PPC) provider. As the field of pediatric oncology moves forward with the goal of curing the nearly 12,000 children who are diagnosed with cancer each year in the United States, the barriers to early integration of palliative care (PC) services for these children are shrinking.<sup>1</sup> Care guidelines from many national organizations, like the American Academy of Pediatrics (AAP),<sup>2</sup> the National Quality Forum (NQF),<sup>3</sup> the Institute of Medicine (IOM),<sup>4,5</sup> the World Health Organization (WHO),<sup>6</sup> International Society of Pediatric Oncology (SIOP),<sup>7</sup> the American Society for Clinical Oncology (ASCO),<sup>8</sup> and others<sup>9</sup> have recommended early integration of palliative care for cancer patients for many years. More recently, systematic reviews have led to recommendations that “youth with cancer should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status” as a standard of care.<sup>10</sup> So why is this only partially ingrained in the practice of pediatric oncology?

In the field of pediatric oncology, most patients will LIVE. The overall cure rate for pediatric cancer patients with varied disease characteristics and stage is around 80%.<sup>11</sup> This amazing statistic is directly related to the tireless efforts of basic and translational scientists and brave clinicians who continue to advance the field! However, this statistic has historically incorrectly been taken to mean that PPC services therefore are only needed for the small portion of the pediatric oncology population who will not be cured. There are few cancer diagnoses in children that portend certain death from the onset, so oncologists interpret population-based survival statistics and apply them to the individual patients they treat. At diagnosis, physicians may have an idea that a patient has a high risk for refractory disease, yet it is not always obvious who will survive. Also, palliative care services have historically been offered late in the disease process. Timing PPC services at end of life is not only suboptimal for the patient's care, but also makes the job of the PPC team much harder AND reinforces the belief that PPC is only offered when “there's nothing left to do.” To provide ideal care for all pediatric oncology patients, the PPC team needs time to build strong relationships and understand how a family makes decisions for their child. By getting PPC teams involved in the care of patients EARLY, relationship building and trust can begin near diagnosis and continue throughout the child's treatment trajectory regardless of outcome. The stigma that receipt of palliative care services is equivalent to “giving up” will be removed as PPC teams are incorporated earlier into the care of any patients with quality of life needs regardless of the outcome of therapy.

But why should pediatric palliative care be integrated into the care of patients who may be cured of their disease? The answer is most children with cancer SUFFER. The data is clear—there remain significant gaps in meeting the needs of these children and families.<sup>12</sup> According to parents of children experiencing a cancer-related death, 89% indicated that their child suffered “a lot” or “a great deal” from at least one symptom in their last month of life.<sup>13</sup> However, reinforcing the perception that suffering is reserved only for families and children nearing the end of life leaves the majority of pediatric oncology patients at risk for unrelieved suffering. Children suffer earlier in therapy—at diagnosis, during months of chemotherapy and weeks of radiation therapy, through hospitalizations and clinic visits and needle sticks. Parents of children with cancer suffer as well—the loss of a

well child, financial stressors, social isolation as they withdraw from work or activities to care for their child, and mental distress from the difficult decisions they are asked to make.<sup>14</sup> Suffering is embedded in the world of pediatric oncology.

The goal of PPC intervention is to reduce suffering—this can be accomplished in many ways and every family may require different services from the palliative care team. Pediatric palliative care teams can provide expert level symptom management for one patient, while emotionally and socially supporting a different family with varying resources and support. The goal remains the same: to provide high quality care that is individualized, evidence-based, patient- and family-centered, and provided in the context of healing relationships. Parents of children with cancer desire and prioritize both cancer-directed therapy and comfort-directed care. Families do not always need to choose—both curative and palliative services can be offered simultaneously, and decisions can be made in the context of prognosis, patient and family goals, available treatment options, and likely outcomes. PPC providers want patients to be cured; we celebrate the victories with families, and remain present if and/or when goals change due to altered disease.

Early integration of pediatric palliative care services is feasible and acceptable to patients, families, and oncologists.<sup>15</sup> In fact, 80% of targeted patients at diagnosis, relapse, or at the time of stem cell transplant proceeded with PPC consultation and neither families nor oncologists objected to these consults.<sup>15</sup> Interestingly, when asked specifically the majority of pediatric oncology providers acknowledge that the ideal time for PPC referral is at diagnosis of cancer.<sup>16,17</sup> In recent work, 48% of pediatric providers<sup>17</sup> and 65% of pediatric oncologists agreed that children should receive PPC services beginning at diagnosis of a life-threatening or incurable cancer. They also simultaneously said that PPC has a negative connotation for patients and families, and this likely influenced their personal referral patterns. This has been dubbed the “they are not ready yet syndrome” and cited anecdotally as a barrier.<sup>18,19</sup> Other proffered barriers include overlap in the provider roles between oncologists and palliative care physicians as well as concern for “conflicting philosophies” among curative and palliative therapies.<sup>19</sup> Newer data, however, shows that the majority of patients and parents identified diagnosis as the preferred time for meeting with the PPC team while many patients and parents stated that optimal involvement of PPC would be “all of a child’s cancer care.”<sup>20</sup>

How do we fully integrate PPC into oncology care? Kaye and colleagues developed a model which depicts PPC integration at three levels: 1) at the consult level where PPC providers connect with patients and families when notified by primary oncology teams, 2) with trigger criteria to capture “higher risk” patients and families automatically, and 3) at an institutional level with PPC education and policy.<sup>21</sup> The consult model is the most familiar—families who have needs are referred to the PPC team by their oncologist, usually late in therapy. However, mutually agreed upon trigger-based consults might serve to identify patients at earlier points for intervention. Finally, an institutional shift due to provision of PPC education and implementation of standard practices supportive of early referral is ideal.

At our institution, the culture has changed significantly due to educational efforts over the last 10 years. All bedside, pediatric oncology nurses are required to complete ELNEC (End-of-Life Nursing Education Consortium) training and are also invited to participate in our bi-annual, multidisciplinary Quality of Life seminar for healthcare providers. The goal of these educational experiences is to lay the foundation for integration of PPC principles into our daily team-based healthcare. By creating an institutional culture that is well versed in PPC goals and services, we hope to de-stigmatize receipt of PPC for patients, families, and providers. We also have developed required communication curriculum for our pediatric hematology-oncology, bone marrow transplant, neuro-oncology, and palliative care fellows. By engaging fellows in efforts to master the skills required for difficult conversations, we allow them to begin these conversations earlier in the therapeutic relationship. Evaluation of this program has shown that fellows feel more confident in their skills and are likely to change their practice based on this education opportunity. Over the same time period, our PPC team has seen a significant increase in the number of referrals and encounters per patient, number of consults requested by all clinical services, and a trend towards earlier consultation with the goal of care shifting from primarily comfort to an increasing emphasis on patients with curative goals.<sup>22</sup>

If a PPC team isn’t available at your institution, patients can still receive primary PPC interventions. This starts with primary oncologists! Pediatric oncologists are dedicated, loving, and involved physicians who remain committed to caring for patients through cure-directed therapy to life prolongation and to death, if necessary. These physicians develop significant bonds with

patients and families and should not be forgotten in discussions of early integration of PC. Through educational resources and training, oncologists can serve as a PPC provider by providing open communication and accurate prognostication, effectively guiding parents through difficult decision making, and offering goal-directed therapy.

Pediatric palliative care is a field which should be embedded into pediatric oncology. Not because the guidelines recommend it, but because children who are referred to PPC services suffer less. Reinforcing the stigma that palliative care teams should only see patients with significantly limited life expectancy or those actively dying dismisses the known benefits to patients and families that the PPC service can provide **throughout** the illness trajectory. The time is NOW and it is the responsibility of each of us to begin to permeate the culture of our institutions to create change in terms of integration of palliative care for children with cancer **early** in their journey towards cure.

## References

- 1 Ries LAG, Smith M, Gurney J, et al. Cancer Incidence and survival among children and adolescents: United States SEER Program 1975-1995. *Natl Cancer Institute, SEER Progr.* 1999;NIH Pub No.
- 2 Schreiner LS, Pimple C, Wolf Bordonaro GP. Palliative Care for Children. *Nurse Educ.* 2009;34(4):162-165. doi:10.1097/NNE.0b013e3181aabde8.
- 3 NQF. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality.*; 2006.
- 4 Medicine I of. *When Children Die: Improving Palliative and End of Life Care for Children and Their Families.* (Field M, Behrman R, eds.). Washington, D.C.: The National Academies Press; 2003. <https://www.nap.edu/read/10390/chapter/1>.
- 5 On Approaching Death C, Key End of Life Issues A, of Medicine I. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. doi:10.17226/18748.
- 6 World Palliative Care Alliance, Connor SR, Sepulveda Bermedo MC. *Global Atlas of Palliative Care at the End of Life.*; 2014. <http://www.who.int/cancer/publications/palliative-care-atlas/en/>.
- 7 Masera G, Spinetta J, Jankovic M, et al. Guidelines for Assistance to Terminally Ill Children With Cancer: A Report of the SIOOP Working Committee on Psychosocial Issues in Pediatric Oncology. *Pediatr Blood Cancer.* 1999;32:44-48.
- 8 Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. *J Clin Oncol.* 2017;35(1):96-112. doi:10.1200/JCO.2016.70.1474.
- 9 Mack JW, Wolfe J. Early Integration of Pediatric Palliative Care: For Some Children, Palliative Care Starts at Diagnosis. *Curr Opin Pediatr.* 2006;18:10-14.
- 10 Weaver M, Heinze K, Kelly K, et al. Palliative Care as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer.* 2015;62:S829-S833.
- 11 O'Leary M, Krailo M, Anderson J, Reaman G. Progress in Childhood Cancer: 50 Years of Research Collaboration, a Report From the Children's Oncology Group. *Semin Oncol.* 2008;35(5):484-493.
- 12 Kassam A, Skiadaresis J, Habib S, Alexander S, Wolfe J. Moving toward quality palliative cancer care: Parent and clinician perspectives on gaps between what matters and what is accessible. *J Clin Oncol.* 2013;31(7):910-915. doi:10.1200/JCO.2012.44.8936.
- 13 Pritchard M, Burghen E, Srivastava DK, et al. Cancer-Related Symptoms Most Concerning to Parents During the Last Week and Last Day of Their Child's Life. *Pediatrics.* 2008;121(5):e1301-e1309. doi:10.1542/peds.2007-2681.
- 14 Rosenberg AR, Dussel V, Kang T, et al. Psychological distress in parents of children with advanced cancer. *JAMA Pediatr.* 2013;167(6):537-543. doi:10.1001/jamapediatrics.2013.628.
- 15 Mahmood LA, Casey D, Dolan J, Dozier A, Korones DN. Feasibility of Early Palliative Care Consultation for Children With High-Risk Malignancies. *Pediatr Blood Cancer.* 2016;63:1419-1422.
- 16 Wentlandt K, Krzyzanowska MK, Swami N, et al. Referral practices of pediatric oncologists to specialized palliative care. *Support Care Cancer.* 2014;22(9):2315-2322. doi:10.1007/s00520-014-2203-6.
- 17 Twamley K, Craig F, Kelly P, Hollowell DR, Mendoza P, Bluebond-Langner M. Underlying barriers to referral to paediatric palliative care services. *J Child Heal Care.* 2014;18(1):19-30. doi:10.1177/1367493512468363.
- 18 Hilden JM. It's Time to Let in Pediatric Palliative Care. *Pediatr Blood Cancer.* 2016;68:583-584.

- <sup>19</sup> Dalberg T, Jacob-Files E, Carney P, Meyrowitz J, Fromme E, Thomas G. Pediatric Oncology Providers Perceptions of Barriers and Facilitators to Early Integration of Pediatric Palliative Care. *Pediatr Blood Cancer*. 2013;60:1875-1881.
- <sup>20</sup> Levine DR, Mandrell BN, Sykes A, et al. Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology. *JAMA Oncol*. 2017;3(9):1214-1220. doi:10.1001/jamaoncol.2017.0368.
- <sup>21</sup> Kaye EC, Friebert S, Baker JN. Early Integration of Palliative Care for Children with High-Risk Cancer and Their Families. *Pediatr Blood Cancer*. 2016;63:593-597.
- <sup>22</sup> Levine DR, Johnson LM, Snyder A, et al. Integrating palliative care in pediatric oncology: Evidence for an evolving paradigm for comprehensive cancer care. *JNCCN J Natl Compr Cancer Netw*. 2016;14(6):741-748. doi:10.6004/jnccn.2016.0076.

## POSITIONING PEDIATRIC PALLIATIVE CARE IN PRIME TIME: PROGRESS HIGHLIGHTS

**Rebecca A. Kirch, JD**

**Executive Vice President for Healthcare Quality and Value**

**National Patient Advocate Foundation**

**Palliative Care Consultant**

**Center to Advance Palliative Care**

**Washington, DC**

**[Rebecca.kirch@npaf.org](mailto:Rebecca.kirch@npaf.org)**

In the evolving value-based health care landscape emerging across the U.S., palliative care is increasingly making its mark as a key aspect of quality care delivery. The evidence base is building, community-based access is expanding, and stakeholders are organizing to help bring palliative care everywhere as an integral part of mainstream medicine.

Pediatric palliative care (PPC) has matured right alongside the adult care field over the past two decades, and this collective momentum tees up important strategic opportunities to embed PPC in the emerging mainstream movement. It requires amplifying the voices of infants, children, and families and articulating their particular needs in chorus as part of the broader cause every chance we get. This article features a few prominent examples where PPC is already positioned to further the field's progress.

### **Collaborative Research**

The Pediatric Palliative Care Research Network (PPCRN) was organized and launched in 2006 to advance the field through innovation and research. Today, the interdisciplinary PPCRN involves multiple sites in the US and Canada. Three of the US sites have conducted prospective cohort studies and a randomized controlled trial, and PPCRN is now conducting two RO1-funded multi-center studies. PPCRN also supports early career investigators by hosting monthly web-based works-in-progress seminars.

In response to outreach by the leadership of PPCRN over the past year, PPC has now been included as a defined priority for the agenda of the Palliative Care Research Cooperative Group (PCRC). Partnered with and generously funded by the National Institute of Nursing Research, PCRC was established in 2010 with a primary goal of helping palliative care investigators overcome the many challenges of conducting multi-site research. PCRC's network has grown to more than 380 members representing over 140 diverse sites across the US and around the world, and this partnership creates pivotal new opportunities for advancing PPC research as part of that expansive platform.

Numerous unanswered questions still exist about improving care outcomes for children with serious illness and their families, and empiric research is critical to finding the answers. Yet PPC research is hindered by challenges such as diverse, small patient populations, developmental considerations, and a limited number of trained investigators. To take the next step in tackling these challenges, PPCRN, PCRC, and the National Palliative Care Research Center (NPCRC) are teaming up to bring research leaders together in Spring 2018 for a PPC State of the Science Conference that will identify barriers and solutions for moving the field forward, as well as research priorities.

Describing the importance of this timely initiative, PPCRN co-chair Dr. Joanne Wolfe of Boston Children's Hospital and Dana-Farber Cancer Institute explained: "Overcoming these challenges requires that we work together, support emerging investigators, and partner with our colleagues studying the care of adults with serious illness. In this way, we can accelerate our pace of discovery and more quickly improve the wellbeing of the children and families we serve."

Deliverables resulting from the State of the Science Conference will include a white paper summarizing the day's proceedings and primary recommendations which will be submitted for peer-reviewed publication. To learn more about PPCRN, PCRC, and NPCRC, view these websites: <http://www.dana-farber.org/research/departments-centers-and-labs/departments-and-centers/department-of-psychosocial-oncology-and-palliative-care/research/pediatric-palliative-care-research-network/>; <http://palliativecareresearch.org> and <http://npcrc.org>.

### **The National Palliative Care Registry**

Having access to program-level data is crucial for developing, sustaining, or expanding a palliative care service, and programs need a plan for measuring and monitoring impact to improve quality, secure influence, and garner support. The National Palliative Care Registry™ was developed by the Center to Advance Palliative Care (CAPC) and NPCRC as an "open source" platform in response to this need. Programs can use the Registry to measure their progress and track their operational capacity and reach. Participation in the Registry is free. CAPC membership is NOT required to participate.

The Registry allows programs to compare their data to those of peers, including patient population (e.g., pediatrics), hospital size, care setting, degree of penetration (percent of annual admissions seen by palliative care), and staffing level. Programs can enter data for one or more service settings and all members of the palliative care team can join the Registry, enter and update data, and view reports. Over the past year, leaders in the PPC field worked directly with the Registry team to improve applicability of the hospital-based survey questions in addressing unique aspects of PPC. Additional tailored improvements for PPC will be made by the end of 2017, including also in the companion community-based setting survey.

**Fifty-two hospital PPC programs** participated in the Registry in 2015/2016. Robust PPC program participation in larger numbers looking ahead will strengthen the ability to create pediatric-specific reports, and will enable further evolution of the database over time to better address the needs of pediatric programs. Participating in the Registry presents a high-yield opportunity for individual programs to help build the national profile of PPC, and the field should strive for 100 percent program participation to really put PPC on the map. There is no cost to participate or to receive data reports. For more information, view the Registry website <https://registry.capc.org> and this blog <https://palliativeinpractice.org/palliative-pulse/palliative-pulse-july-2017/spotlight-pediatric-palliative-care-national-landscape-hospital-based-programs-2015-2016/>.

### **Mapping Community Palliative Care**

In collaboration with the National Coalition for Hospice and Palliative Care, CAPC has also launched *Mapping Community Palliative Care*, a three-year project funded by the Gordon and Betty Moore Foundation that is building a comprehensive inventory of community palliative care programs across health care settings. The information collected will be used to track the growth of palliative care over time and develop estimates of palliative care access and prevalence in communities across the country.

This initiative will support the expansion of community palliative care by identifying models of service delivery and providing summary data for the field. It will also make it easier for patients, families, caregivers and practitioners to find palliative care services in their community. Participating palliative care programs also have the option of being publicly listed for patients and families on the Provider Directory at [getpalliativecare.org](http://getpalliativecare.org), where program information will include population served. Participating in this initiative presents another key opportunity to raise the visibility of PPC as part of the national quality care landscape. For more information and to put your program on the map, go to the project website at <https://mapping.capc.org>.

### **The National Consensus Project**

To support palliative care's evolution in meeting the needs of patients and families coping with serious illness at any age and any stage, stakeholders are convening under the coordinated leadership of the National Coalition for Hospice and Palliative Care to

update the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP). Funded under a grant from the Gordon and Betty Moore Foundation, this two-year project will build on the success of the NCP 3rd edition by improving access to quality palliative care for all patients and families in need and in all care settings.

The project officially launched in June 2017 with a Stakeholder Strategic Directions Summit in Chicago that brought together over 60 representatives from 43 national organizations covering a broad range of care settings, professional associations, patient and caregiver advocates, accrediting bodies, payers, and community services organizations. This updated NCP effort will focus on formalizing, delineating, and disseminating evidence-based processes and practices for the provision of safe and reliable high-quality palliative care for adults, infants, children, and families with serious and/or chronic progressive illness across the care continuum and all care settings. Ultimately, the guidelines will be a vital resource for encouraging organizations and clinicians throughout the continuum to integrate palliative care principles and best practices into their routine patient assessment and care.

PPC is represented on both the NCP steering and writing committees, and a broader band of stakeholders involved in caring for infants and children in various settings will also have opportunities to provide input throughout the project. Dr. Sarah Friebert of Akron Children's Hospital, currently serving on the NCP steering committee, highlighted the shared issues that adult and PPC practitioners confront in coordinating care across the continuum and transitions, noting that "the entire palliative care field has so much to gain by joining forces in creating these updated NCP consensus guidelines that cover the full life span and all care settings, with emphasis on continuity and family-based care."

The publication date for the NCP 4th Edition is planned for July 2018. For more information visit [www.nationalcoalitionhpc.org/ncp](http://www.nationalcoalitionhpc.org/ncp) and view this blog <https://palliativeinpractice.org/palliative-pulse/palliative-pulse-september-2017/palliative-care-comes-of-age/>.

### **Policy Pursuits**

Through its Roundtable on Quality Care for People with Serious Illness launched in mid-2016, the National Academies of Sciences, Engineering and Medicine (formerly the Institute of Medicine) is convening key stakeholders to foster an ongoing dialogue about critical policy and research issues to accelerate and sustain progress in serious illness care for adults and children of all ages. Roundtable membership includes patient advocates, health care professional organizations, health care providers and insurers, foundations, federal agencies, researchers, and others interested in improving care for people with serious illness.

The Roundtable is hosting a series of workshops over three years, with the first three to be completed in 2017. The agenda for each workshop includes emphasis addressing the needs of seriously ill infants and children and the families who care for them as part of the broader discussion under each topic. Presentations and publications from the first two workshops are available online, and include compelling stories and professional insights from PPC patients and professionals:

■ Integrating the Patient and Caregiver Voice into Serious Illness Care (December 15, 2016) workshop presentations <http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2016-DEC-15.aspx>

■ Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care: A Workshop (April 27, 2017) <http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2017-APR-27.aspx>

Roundtable resources and resulting publications are available online at <http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx>.

Nationwide palliative care advocacy is also advancing through efforts of the Patient Quality of Life Coalition (PQLC). Formed in 2013 and currently comprised of more than 40 member organizations, PQLC is dedicated to improving quality of care and quality of life for seriously ill adults and children through promotion of public policy that will improve and expand access to high quality palliative care.

In particular, PQLC is working to gain support for and pass the Palliative Care and Hospice Education and Training Act (PCEHTA, H.R. 1676/S. 693), legislation that will improve care quality and the quality of life of patients, families, and caregivers coping with serious illness by improving and expanding palliative care awareness, access, training, and research. PQLC has a dedicated PPC workgroup that helps keep the voices of infants, children, and families at the forefront of its advocacy activities. Visit the PQLC website to learn more about its priorities and how your program or professional organization can participate by taking action. <http://patientqualityoflife.org>

These initiatives illustrate how effective advocacy through a variety of PPC leadership steps is accelerating progress in the field. To access a comprehensive catalog of resources, tools, and training to promote PPC innovation and growth, check out the material featured at this link, including a PPC resources field guide and companion slide deck focused on making the case for PPC. <https://www.capc.org/topics/pediatric-palliative-care/>

## STATEWIDE PEDIATRIC PALLIATIVE CARE COALITIONS

*Devon Dabbs*

Vice President, Pediatric Programming and Education  
Coalition for Compassionate Care of California  
[ddabbs@coalitionccc.org](mailto:ddabbs@coalitionccc.org)

*Kate Detwiler*

Executive Director, Alliance Kids (mid Atlantic region)  
[HospiceAlliance.Peds@gmail.com](mailto:HospiceAlliance.Peds@gmail.com)

*Betsy Hawley*

Executive Director, Pediatric Palliative Care Coalition (Pennsylvania)  
[betsy@ppcc-pa.org](mailto:betsy@ppcc-pa.org)

*Kristin James*

Executive Director, Greater Illinois Pediatric Palliative Care Coalition  
[kjames@gippcc.org](mailto:kjames@gippcc.org)

As increasing numbers of children return home from hospital-based NICU/PICU care, they bring life-sustaining technologies, rare diseases, and chronic/complex conditions with them into their communities. As the number of these medically-involved and technology-dependent children has grown, their medical teams and home communities have looked for systems to support and serve these children and their families, often in ways that are uniquely suited to each state or region. More and more of these collaborations are formalizing as coalitions.

Each state or regional coalition is unique and not every state houses an organized coalition. Some coalitions cover entire regions, such as Alliance Kids which includes Maryland, Delaware, Northern Virginia, and Washington, DC. Others, like those in South Carolina and Kansas are a group of committed clinicians working together on issues relevant in their state's particular needs. The Children's Palliative Care Coalition of Michigan was founded by a bereaved family as a way of creating a better system of palliative care for children.

Some coalitions are independent 501(c)(3) organizations, like the Pediatric Palliative Care Coalition in Pennsylvania (PPCC) and Alliance Kids (mid Atlantic region). Still others have partnered with similarly-minded organizations in their state with a primary focus on adults. Still others, like Children's Hospice and Palliative Care Coalition (CHPCC) formerly an independent 501(c)3 organization, formalize partnerships with coalitions or organizations focused on adults but which share a like-minded mission.

Advocacy and education often drive the formation and activities of a coalition. However, each organization has its own individual objectives that best address the needs of its community. Many exciting initiatives are happening all across the country in statewide pediatric palliative care coalitions.

- In order to address the specific education needs for rural practitioners, the Illinois coalition (GIPPCC) created a nurse and physician mentorship program, partnering those new to the field or inexperienced with pediatrics with knowledgeable, veteran, pediatric palliative care nurses and physicians.
- Tremendous advocacy efforts in California have led to a successful pediatric palliative care waiver program, where qualified children are able to access supportive care services based on diagnosis rather than prognosis. CHCCP developed relationships with leaders in state programming, while also fostering an effective and progressive system for Concurrent Care implementation.
- Pennsylvania’s coalition (PPCC) provides resources for caregivers and families. Their Care Plan Book is an indispensable tool to help families organize all the accumulated health care data needed for their children. The coalition is in the development stage of a digital version of the Care Plan Book which will allow quick access to all needed information on an electronic device.
- While all of the coalitions host educational programming, the Texas Pediatric Palliative Care Consortium holds an outstanding symposium each year with nationally recognized speakers.

As the field grows, there is increased interest among coalitions in collaborating across state lines to work on areas of common interest with the hope of making a greater impact. While each state has unique and individual needs, there are many shared issues and visions. This offers tremendous potential for collaborative ventures. Opportunities abound for joint programming and increased advocacy efforts. Being aware of what is happening in other states regarding issues such as Concurrent Care, Medicaid, and legislative or regulatory efforts, opens the door to possibilities in our individual states, offering fresh, concrete ideas to present to our own legislators. By coming together we can make a much stronger impact on national issues such as the Palliative Care and Hospice Education and Training Act (PCHETA) bill, as well as CHIP and Medicaid legislation.

One of the most exciting projects coming out this year is the 2018 Pediatric Palliative Care Webinar series. A collaboration between the coalitions in California, Illinois, and Pennsylvania, the webinar series was created to raise the visibility of pediatric palliative care in the United States and to provide applicable, affordable, and practical education from leaders in the field of pediatric hospice and palliative care. This project has allowed finite resources to be used judiciously to reach an amplified audience.

To find out if you have a pediatric palliative care coalition in your state, see the attached chart. There may be others that we are not aware of, please let us know. If you are interested in forming a coalition or learning more about current work, feel free to reach out to any of the authors to share ideas.

In the words of Ryunosuke Satoro, “Individually, we are one drop. Together, we are an ocean.”

### Pediatric Palliative Care Coalitions Throughout The United States

STATE	NAME	CONTACT	WEBSITE
California	Children’s Hospice and Palliative Care Coalition	Devon Dabbs <a href="mailto:ddabbs@coalitionccc.org">ddabbs@coalitionccc.org</a>	<a href="http://www.coalitionccc.org">www.coalitionccc.org</a>
Illinois	Greater Illinois Pediatric Palliative Care Coalition	Kristin James <a href="mailto:kjames@gippcc.org">kjames@gippcc.org</a>	<a href="http://www.gippcc.org">www.gippcc.org</a>
Kansas	Kansas Hospice and Pediatric Palliative Care Coalition	Kathy Davis <a href="mailto:Kdavis2@kumc.edu">Kdavis2@kumc.edu</a>	
Maryland	Alliance Kids	Kate Detwiler <a href="mailto:kate.detwiler@gmail.com">kate.detwiler@gmail.com</a>	

STATE	NAME	CONTACT	WEBSITE
Michigan	Children's Palliative Care Coalition of Michigan	Richard Graham-Yool <a href="mailto:Richard@childpalliative.org">Richard@childpalliative.org</a>	<a href="http://www.childpalliative.org">www.childpalliative.org</a>
Minnesota	Pediatric Palliative Care Coalition of Minnesota	Jody Chrastek <a href="mailto:jchrast1@fairview.org">jchrast1@fairview.org</a>	<a href="http://www.mnhpc.org/individuals/pediatric-palliative-care/ppccmn/">www.mnhpc.org/individuals/pediatric-palliative-care/ppccmn/</a>
Missouri	Pediatric Palliative Care Coalition of Missouri	Joan L. Rosenbaum <a href="mailto:Rosenbaumj@wustl.edu">Rosenbaumj@wustl.edu</a>	
New York	Hospice and Palliative Care Association of New York	Beth Mahar <a href="mailto:bmahar@hpcanys.org">bmahar@hpcanys.org</a>	<a href="http://www.hpcanyspediatricpalliativecare.org">www.hpcanyspediatricpalliativecare.org</a>
North Carolina	Pediatric Palliative Care Coalition of North Carolina	Dan Mackey <a href="mailto:danmackey08@gmail.com">danmackey08@gmail.com</a> Lily Gilmore <a href="mailto:lgillmor@transitionslifecare.org">lgillmor@transitionslifecare.org</a>	
Ohio	Ohio Pediatric Palliative Care and End of Life Network (OPPEN)	Mary Kay Tyler <a href="mailto:MKTyler@HospiceWR.org">MKTyler@HospiceWR.org</a>	
Pennsylvania	Pediatric Palliative Care Coalition	Betsy Hawley <a href="mailto:betsy@ppcc-pa.org">betsy@ppcc-pa.org</a>	<a href="http://www.ppcc-pa.org">www.ppcc-pa.org</a>
South Carolina	South Carolina Pediatric Palliative Care Collaborative	Conrad Williams <a href="mailto:wilcon@musc.edu">wilcon@musc.edu</a>	
Texas	Texas Pediatric Palliative Care Consortium	Jan Wheeler <a href="mailto:jwheel3983@aol.com">jwheel3983@aol.com</a>	<a href="http://www.texasppcc.org">www.texasppcc.org</a>

## FUTURE VISIONS FOR PEDIATRIC PALLIATIVE CARE

**Brian Carter, MD**

**Professor of Pediatrics**

**University of Missouri Kansas City**

**School of Medicine**

**Kansas City, MO**

[bscarter@cmh.edu](mailto:bscarter@cmh.edu)

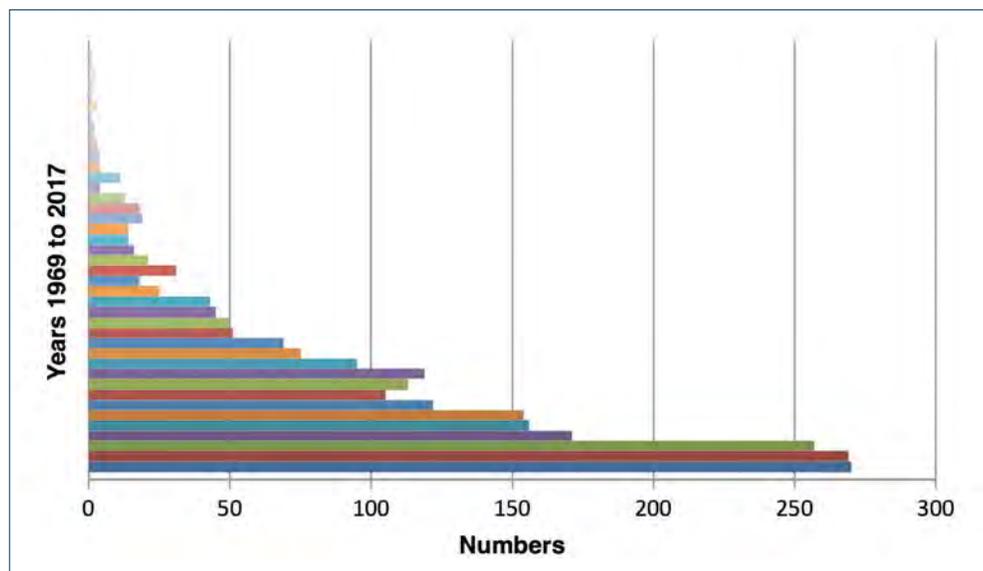
In 1960, Klaus Patau, PhD from Germany and an international group of authors reported in *The Lancet* the first case of trisomy 13 (subsequently referred to as Patau's syndrome). Of note, the little girl was 13 months of age, surviving with congenital heart disease, cleft lip and palate, anophthalmia and polydactyly. The report was in the same issue of *The Lancet* where John Edwards, MD from the UK first described trisomy 18 (subsequently referred to as Edward's syndrome). It was a heady time in pediatrics at the dawn of medical genetics – the naming convention for human chromosomes was held in Denver that same year.

Over the past 50 years each decade has brought an increasingly hopeful, and bright, future for children in North America. Hematologic cancers now have around 85% 5-year cure rates; premature infants weighing > 1000 grams nearly all survive and 85% have no significant neurodisability in childhood; cystic fibrosis patients are living well into adulthood; and children with spina bifida are diagnosed prenatally – and even receive surgical interventions in the middle of gestation! Today's children's hospitals are occupied by surgical patients, many of whom are having corrections for birth differences. Inpatients on the wards or in private rooms often have related genetic conditions, or chronic illnesses. And many patients frequenting the pediatric ICU are primarily managed at home on assistive technology such as ventilators, dialysis, or feeding tubes/pumps.

Pediatric palliative and hospice medicine has a bifid history. One historical origin accommodates children much like adult patients receiving palliation for ultimately terminal conditions...significant cancers, neurodegenerative disorders, or chronic organ system failure. The provision of palliative and hospice care seems to be “added to” an extant cure-oriented and life-extending paradigm of care as the looming end-of-life nature of the condition becomes more evident. Potential curative benefits give way to burdens of continued in-hospital, ICU, or other life-sustaining medical treatments. The other contributing stream to palliative care for infants, children, and adolescence is that of early adoption of concurrent palliative support even before birth in fetal diagnostic centers, while a newborn is cared for in the neonatal ICU, or from the point of diagnosis for a school-aged child with cancer. In this paradigm, the added value of an interdisciplinary team, psycho-social-spiritual support, and expert pain and symptom management are acknowledged as enhancing the child and family’s quality of life even while cure-oriented or disease modifying treatments are offered. The focus is on the quality of life and relationships while living with a life-limiting condition.

There have been hallmark pieces within the clinical literature that have spoken to the value of a palliative or hospice paradigm of care being introduced in pediatrics over the past 30 years. In 1982, neonatologists, pediatricians, and a pediatric social worker in Denver first wrote of the potential benefits of applying hospice concepts to neonatal care [Whitfield, et al. 1982]. A decade later Dr. Alan Fleischman and colleagues wrote a landmark article in *Pediatrics* addressing how pediatricians should respond to gravely ill children [Fleischman, et al. 1994]. And thereafter in the early 2000’s came works from Dr. Joanne Wolfe [*N Engl J Med*, 2000] and others demonstrating the need for improved symptom management – initially for those children with cancer at the end of life, but increasingly addressing all age and diagnostic groups. Now, in 2017 there are no less than four major textbooks in pediatric palliative care, regional and national pediatric continuing education conferences for nurses and physicians regularly include palliative care topics, at this writing texts are forthcoming in neonatal-perinatal palliative care and leading neonatology and pediatric textbooks now include the address of palliative and hospice medicine. The American Academy of Hospice and Palliative Medicine addresses pediatric topics regularly as does the Center to Advance Palliative Care, and the Section on Hospice and Palliative Medicine of the American Academy of Pediatrics is approaching its 10th year of existence.

**Pediatric Palliative Care Annual PubMed Entries Over 50 Years**



At this juncture, what might the future look like for pediatric palliative care?

I will outline three major considerations for the field in the next decade. First, given the rapid expansion of genomic and personalized medicine, I believe that pediatric palliative care (PPC) clinicians will need to acquire a working facility with the new genetics, genomics, and individualized pharmacogenomics. The potential for prenatal diagnostics of not only phenotypic abnormalities, but also genetic and genomic diagnoses will impose an additional layer to fetal, perinatal, and neonatal decision-

making. The possibility of expanded genome-wide newborn screening is no longer science fiction. To date, such additional information has, on occasion, yielded insights toward therapeutics and prognostication for some babies and families. But equally common is obtaining information that is of questionable value (variants of unknown significance) – or even that for which no sound prognostication can come. Will these prove daunting and add additional twists and turns in a care team's or family's diagnostic – or therapeutic – odyssey? I'm sure they will. Will the general public be able to digest the potential, real, or relative import of newly named or defined conditions even while their attendant prognoses remain to be defined? Only with our help as PPC clinicians, generally adept with superlative communication skills, find their place amid the likely therapeutic optimism of parental, child, and even clinician hopefulness.

A second area of future import for PPC clinicians will be the continued momentum for the field to advocate that PPC services be initiated concurrently with intensive care, oncologic care, and the treatment of chronic and complex pediatric health care conditions. While progress has been made in the establishment of PPC teams across North America, their presence and composition – and hence their service capacity – remains variable. Some 'teams' consist of a PPC Nurse-Practitioner working with unit-specific Social Workers, Nurses, and Physicians, and hospital-wide Child-Life Specialists or Chaplains; while others staff true PPC interdisciplinary teams that see patients and families throughout the hospital, in specialty clinics, and even at home. The specialty will need to continue its encouragement for hospital and clinic administrators to provide true interdisciplinary staffing – making it more likely that specialty expertise is developed, rather than palliative care simply being an additional matter heaped upon otherwise untrained and often overburdened unit-specific staff.

Finally, PPC clinicians need to advance not only qualitative work and the development of best practice models, but also conduct research that will advance the field. Such efforts might be aimed at symptom assessment and management; medication trials and studies; access to PPC services across broad geographic regions and away from tertiary children's specialty hospitals. There should be regional and national investigation of how well adult PC and hospice providers can, and do, accommodate pediatric patients and families. Research networks will need to look at the integration of PPC into the medical home and how accountable care organizations (ACOs) ensure access to, and work with, PPC expertise.

The past informs the present and lays the groundwork for what I believe to be a bright, yet challenging, future for PPC. It will require continued hard work, insightful young leaders, and energized parents, clinicians, and policymakers working together in advocacy and legislative channels to ensure the place of the specialty within the breadth of essential benefits for children in North America. These children will not only include the trisomy patients first described over 50 years ago – for whom many of us did not originally believe benefit lay in any life-supportive technology. They now, and in the future, will include children with yet to be defined diagnoses, children with life-limiting, life-threatening, and certainly life-modifying conditions – all of whom deserve our best, for all the days of their lives.

## References

1. Robinson A. SPECIAL CONTRIBUTION. *JAMA* 1960; 174(2):159–162.
2. Whitfield JM, et al. "The application of hospice concepts to neonatal care." *Am J Dis Child* 1982; 136(5): 421-424.
3. Fleischman AR, et al. Caring for gravely ill children. *Pediatrics* 1994; 94:433-9.
4. Wolfe J, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000; 342(5):326-33.
5. Petrikin JE, et al. Rapid whole genome sequencing and precision neonatology. *Semin Perinatol* 2015; 39(8):623-31.

## 10 INTERESTING RESEARCH QUESTIONS IN PEDIATRIC PALLIATIVE CARE

*Harold (Hal) Siden, MD, MHSc, FRCPC*

Medical Director, Canuck Place Children's Hospice

Medical Director Palliative Care and

Research Institute Investigator, BC Children's Hospital

Clinical Professor, Department of Pediatrics

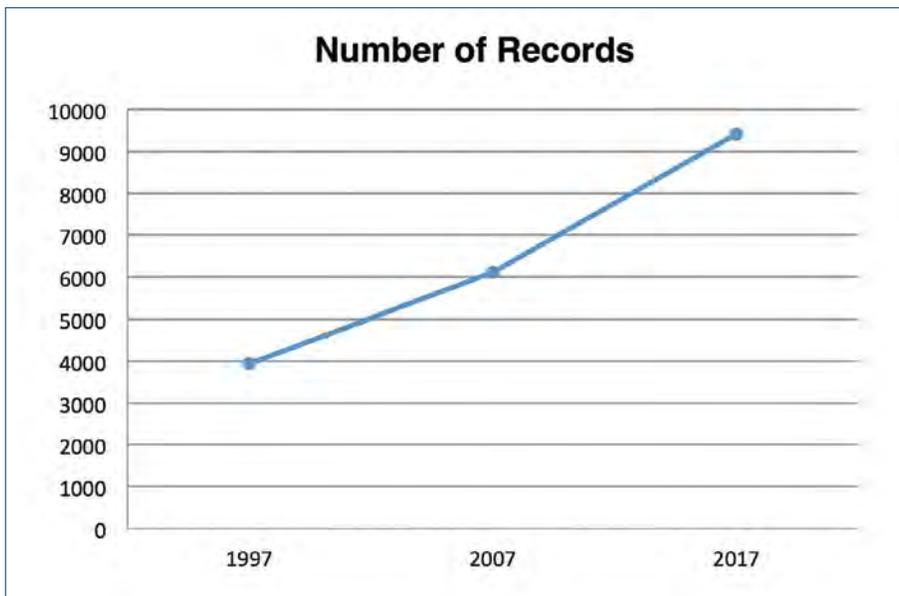
University of British Columbia

[hsiden@cw.bc.ca](mailto:hsiden@cw.bc.ca)

Every few years we see compilations of important research questions in pediatric palliative care, for example in 2008 (1) and 3 more since 2016 (2–4).

I was asked by the editors to provide my personal perspective on the question: What are 10 interesting research questions to be answered in the field of pediatric palliative care in 2018 and beyond? To begin, I looked at research publications in pediatric palliative care 20 years ago, 10 years ago, and this year with the help of Colleen Pawliuk, the PedPalASCNet librarian, based at the BC Children's Hospital Research Institute. Colleen coordinates the production of our monthly citation list "Trends in Pediatric Palliative Care Research."

Using only MEDLINE we looked at publications across the 20 year span. The search strategy used was the same that we use in generating the monthly list, but without the additional databases we currently search. These numbers are annual, and don't include the second-round, hands-on filtering that has to occur each month, even with a well-refined search strategy. Not surprisingly, there is a steady increase in articles over 20 years—196 publications in 1997, 269 in 2007, and 144 in 2017. Why the lower figure in 2017? It's likely because the databases are not updated immediately and it takes time for a publication to enter Medline. When we look instead at 2016 the ongoing trend is clear; 320 articles published in that year. Figure 1 shows another view of how publications have accumulated over time.



One striking difference is the nature of the articles. In 1997 a substantial number of articles focused on the ethics of pediatric palliative care; when it should be offered, whether treatment should stop, what children should be told. By 2007, there were proportionally more articles reporting the results of research projects—many focused on the experiences and perspectives of family, explored either through surveys or qualitative approaches.

In 2017, based on the selections from the TPPCR list, there was a more diverse set of reports spanning a number of questions of importance to clinicians (and we hope to families). These reports helped me establish this list of research questions to be answered. Not all of the articles were published in 2017; some are older as the January search includes the end of the prior year, while other articles were first included in the index databases in 2017.

In no particular order, here are 10 research questions that I would like to see addressed with references to the topic collected from TPPCR 2017. Readers may have an entirely different set, and I hope they do!

**Question 1: How is pediatric palliative care [best] provided for children with non-cancer diagnoses?**

Even though it was recognized early on in the development of the field that many children requiring palliative care have a non-cancer diagnosis, a number of initial studies focused on the care of children with cancer. Now we are seeing the emergence of research examining how PPC is provided, and should be provided, to children and families living with heart disease, renal disease, genetic-neurological conditions, and others. There is not one monolithic diagnosis called “non-cancer”; instead, each of these deserves its own attention as the palliative care experience may have differences based on potential treatment options and disease course (5–29).

**Question 2: How do we engage in Advance Care Planning and Advance Directives discussions with children and families?**

Research using a variety of methods—survey, qualitative interview, health research data, and observational studies—is beginning to yield answers to “how to.” It is clear that there is no one-size-fits-all approach, nor a series of a few magic words that will make the conversation easy. Instead research is exploring difficult conversations in a variety of settings (NICU, PICU, Emergency Rooms) and with different participants (parents of children with chromosomal conditions, adolescents, and others). Given that “the conversation” is a fundamental component of PPC, developing increasing understanding of the structure and process, and testing that understanding, is a fundamental research pursuit for the field (30–38).

**Question 3: How do we talk to children about their hopes, goals, and fears?**

I have been actually struck, now that I have noticed it, by how much of the dialogue we have in Pediatrics is with parents and not with children. As an attending physician on the General Pediatrics unit, I saw residents acquire increasing confidence in speaking to parents, but not significant change in their relationship to their patients beyond developing a calming and comforting approach. Franco Carnevale's work is focusing on this issue (39), but it goes back to Myra Bluebond-Langer's foundational study of children dying of cancer (40).

The answer to this research question in part has to do with professional education. Counselors (psychologists, social workers) acquire these skills, often using expressive modalities such as art or play. How do we teach medical and nursing clinicians a set of definable competencies in having challenging conversations with children? Many reports found in TPPCR in 2017 described educational programs for learners at all levels across disciplines. We need to make sure that the content of those educational interventions include communication with children (41–51).

**Question 4: Are there prognostic markers for fragility and early death, especially in children with static encephalopathies such as severe neurological impairment due to hypoxia or structural brain dysgenesis?**

That question may seem like a mouthful. In more practical terms we know that some conditions (e.g., cancer, metabolic storage diseases) are inherently progressive. Others carry a life-long risk of acute deterioration in the setting of a chronic condition (e.g., pulmonary hypertension with congenital heart disease). There are, however, many children followed by PPC teams who have static conditions such as the two in the question. Some of these children will live well into adulthood, although requiring ongoing, daily care for their functioning and their health. Others, inexplicably it seems, will experience deterioration in health, often between the ages of 5 and 15, and die. While the immediate cause of death may be due to events such as pneumonia or worsening seizures, it is apparent that deterioration was occurring already.

Are there biomarkers of this deterioration, perhaps identifiable through a metabolomics approach that would signal the change? Patterns of inflammatory and immunologic markers may hold a clue. The benefit of anticipating decline might help with providing supportive, comfort care, avoiding futile interventions, and building in family support, even if it did not identify a reversible process (52,53).

**Question 5. Do our current treatments for pain work? What is the evidence for new assessment tools and treatments for the other symptoms children experience?**

If having cogent conversations with parents and children is one fundamental skill in PPC, the other *sine qua non* is being able to manage pain and other symptoms. It was notable that in the 2017 TPPCR there were few articles describing new research in symptom assessment or treatment.

Pain receives a modest amount of attention, but many other symptoms affecting children and ones that parents report as troubling, are not being addressed or at least not in the publications we found. Physical symptoms of importance include fatigue, dyspnea, gastro-intestinal symptoms (nausea & vomiting, constipation), dysomnia, temperature instability, secretions, and salivation. These symptoms need better evaluation in both children with cancer and those with the numerous non-cancer conditions, given the wide heterogeneity of disease mechanisms, treatments, and symptoms.

Similarly, little focused attention has been paid to evaluation of our emotional interventions; when we identify depression, anxiety, fear, and recommend “counseling”; what works, what doesn’t, especially in the context of progressive disease (54–69).

**Question 6. Who are the children that do receive, and who are those that should receive, pediatric palliative care?**

One mark of the growth, perhaps it is fair to say maturation, of the field is that more and more we understand the children who live at risk of dying young. Early work in this area was done by Chris Feudtner with his foundational studies of children with complex, chronic conditions (70,71). We continue to learn more about the populations of children who should have the opportunity to access pediatric palliative care service, through work by Lorna Fraser, Kim Widger, and others who are interrogating large health-services datasets. Answering this question will help with health services planning and educational initiatives. It will have implications for the future of PPC programs in the evolving healthcare environment (72–91).

**Question 7. What are the outcomes of pediatric palliative care of importance, and how do we structure services to achieve these outcomes?**

It goes without saying that we need meaningful outcomes—meaningful to children and to their families. These must be measurable in some way as well in order to determine how to establish services. There are descriptions of various team structures and service delivery models for PPC, sometimes in different health systems but other times found within the same system. The optimal model depends on what we are trying to achieve—and this is a challenging question when it comes to measurement. Progress is being made; there is better understanding of processes and their measurement, and the emergence of a discussion about measureable outcomes. Despite the interesting work cited in TPPCR 2017, we are still not there yet (92–105).

**Question 8. Do we understand parental grief and bereavement sufficiently to make strong recommendations regarding service provision?**

As can be seen from this review of TPPCR 2017, and other literature reviews from many other years, we are learning a lot about the experience of grief and bereavement for parents, and increasingly so for siblings. Clearly, there is no one single approach to providing support in bereavement; modifications must be made to accommodate the unique experience and situation of each family. However, the huge variability in service provision implies that the evidence base has not generated an envelope of best practices that leaders, administrators, and advocates can rely on for planning (106–116).

**Question 9. What is, and will be, the impact of assisted death in children on pediatric palliative care?**

A better way of phrasing this question is simply: “Medical Aid in Dying?” At this point the topic is so new and broad it is hard to know all of the questions we will need to answer. They range across ethics, practice, impact on families and clinicians.

Physician-assisted death for children already exists in law, policy, and practice, for example in the Netherlands. It is new, however, to North America with the passage of the 2016 law in Canada. The current law explicitly excluded “Mature Minors” and gave Parliament a period of time to decide whether and how to create a legal regime for assisted death in this group. The issue has been sent out for study with a report due in late 2018. (The other groups under similar study are individuals with mental illness as the sole underlying condition, and those wishing to incorporate MAID into their Advance Directives).

There have been reports from the experience in the Netherlands and other jurisdictions, but given the reach of the current Canadian law and the vocal debate, what happens in Canada for minors, mature and otherwise, will likely have a significant impact.

In Canada, while PPC clinicians are in the majority opposed to MAID for children, we are seen as the experts in death and dying and are called upon to engage in the issue. Several clinicians are currently members of the committee studying the issue for Parliament and serving as advisors in provincial programs. Therefore it is an issue that we will be asked to think about and study, whether we are ready or not (117–120).

**Question 10. What are the fundamental elements of palliative care that should be applied in every setting and what are the means to provide that in less-well resourced countries?**

Pediatric palliative care embodies an irony—as medicine in industrialized nations has gotten better and better at treating and curing life-threatening conditions in childhood (cf., gene-therapies for SMA; CAR T-cell treatment for leukemia), we have actually increased our attention on palliation.

Developing nations still have high rates of child and infant mortality, often due to reversible conditions secondary to malnutrition, lack of clean water, and lack of vaccinations. When it comes to the myriad conditions that PPC practitioners follow in non-industrialized nations, there is no opportunity for treatment. How then is palliative care provided? What are the core elements of that provision, and what creative ways are people addressing the need? What lessons can we learn from those experiences? (121–126)

**References**

1. Steele R, Bosma H, Johnston MF, Cadell S, Davies B, Siden H, et al. Research priorities in pediatric palliative care: a Delphi study. *J Palliat Care*. 2008;24(4):229–39.
2. Beecham E, Hudson BF, Oostendorp L, Candy B, Jones L, Vickerstaff V, et al. A call for increased paediatric palliative care research: Identifying barriers. *Palliat Med*. 2016 Dec;30(10):979–80.
3. Lioffi C, Anderson A-K, Howard RF, On behalf of NCRNCCSG in P, Care P. Development of research priorities in paediatric pain and palliative care. *Br J Pain*. 2017;11(1):9–15.
4. Quinn C, McCarthy S, Devins M, O'Reilly M, Twomey M, Ling J. Prioritisation of future research topics in paediatric palliative care in Ireland: a Delphi study. *Int J Palliat Nurs*. 2017;23(2):88–97.

**Question 1: How is pediatric palliative care [best] provided for children with non-cancer diagnoses?**

5. Arthur J, Gupta D, Arthur JD. “You Can Carry the Torch Now:” A Qualitative Analysis of Parents’ Experiences Caring for a Child with Trisomy 13 or 18. *HEC Forum*. 2017;29(3):223–40.
6. Balkin EM, Kirkpatrick JN, Kaufman B, Swetz KM, Sleeper LA, Wolfe J, et al. Pediatric Cardiology Provider Attitudes About Palliative Care: A Multicenter Survey Study. *Pediatr Cardiol* [Internet]. 2017; Available from: <https://www.ncbi.nlm.nih.gov/pubmed/28664445>
7. Brown AM, Nelson BH, Beuscher LM. Access and Barriers to Utilization of Palliative Care in Pediatric Pulmonary Hypertension. *J Hosp Palliat Nurs*. 2017;19(5):474–9.

8. DeCoursey DD, Silverman M, Oladunjoye A, Balkin EM, Wolfe J. Patterns of Care at the End of Life for Children and Young Adults with Life-Threatening Complex Chronic Conditions. *J Pediatr*. 2017 Nov 21;
9. Dellon E, Goldfarb SB, Hayes D Jr, Sawicki GS, Wolfe J, Boyer D. Pediatric lung transplantation and end of life care in cystic fibrosis: Barriers and successful strategies. *Pediatr Pulmonol* [Internet]. 2017 Aug; Available from: <http://dx.doi.org/10.1002/ppul.23748>
10. Donald A, Kauffmann L, Ram D, Vassallo G. End of life care in paediatric neurodegenerative disease: A regional experience. *Dev Med Child Neurol*. 2016 Jan 1;0:42nd Annual Conference of the British Paediatric Neurology Association, BPNA 2016. United Kingdom. Conference Start: 20160127. Conference End: 20160129. 58 (pp 75).
11. Duc JK, Herbert AR, Heussler HS. Paediatric palliative care and intellectual disability-A unique context. *J Appl Res Intellect Disabil*. 2017 Aug 23;
12. Hoell JI, Warfsmann J, Gagnon G, Trocan L, Balzer S, Oommen PT, et al. Palliative care for children with a yet undiagnosed syndrome. *Eur J Pediatr*. 2017 Aug 14;
13. Hollander SA, Dykes J, Chen S, Barkoff L, Sourkes B, Cohen H, et al. The End of Life Experience of Pediatric Heart Transplant Recipients. *J Pain Symptom Manage* [Internet]. [cited 2017 Jan 26]; Available from: [www.sciencedirect.com/science/article/pii/S0885392416312350](http://www.sciencedirect.com/science/article/pii/S0885392416312350)
14. Higgs EJ, McClaren BJ, Sahhar MAR, Ryan MM, Forbes R. "A short time but a lovely little short time": Bereaved parents' experiences of having a child with spinal muscular atrophy type 1. *J Paediatr Child Health*. 2016;52(1):40–6.
15. Jaiswal N, Singh M, Agarwal A, Thumburu KK. Palliative drug treatments for breathlessness in cystic fibrosis. *Cochrane Database Syst Rev*. 2017 Aug 10;8:Cd011855.
16. Kazmerski TM, Weiner DJ, Matisko J, Schachner D, Lerch W, May C, et al. Advance care planning in adolescents with cystic fibrosis: A quality improvement project. *Pediatr Pulmonol*. 2016 Dec 1;51(12):1304–10.
17. Keefer P, Lehmann K, Shanley M, Woloszyk T, Khang E, Luckritz K, et al. Single-Center Experience Providing Palliative Care to Pediatric Patients with End-Stage Renal Disease. *J Palliat Med*. 2017 Aug;20(8):845–9.
18. Lindley LC. Multiple Complex Chronic Conditions and Pediatric Hospice Utilization among California Medicaid Beneficiaries, 2007-2010. *J Palliat Med*. 2017 Jan 1;20(3):241–6.
19. Lindley LC, Colman MB, Meadows JT Jr. Children with intellectual disability and hospice utilization. *J Hosp Palliat Nurs*. 2017 Jan 1;19(1):28–33.
20. Lindley LC, Keim-Malpass J. Quality of paediatric hospice care for children with and without multiple complex chronic conditions. *Int J Palliat Nurs*. 2017;23(5):230–7.
21. Marcus KL, Balkin EM, Al-Sayegh H, Guslits E, Blume ED, Ma C, et al. Patterns and Outcomes of Care in Children with Advanced Heart Disease Receiving Palliative Care Consultation. *J Pain Symptom Manage*. 2017;
22. Masood Y, Spiers H, Cragie R, Edi-Osagie N. Surgical intervention in trisomy 18-supporting palliative care. *Arch Dis Child*. 2017;Conference:Annual Conference of the Royal College of Paediatrics and Child Health, RCPCH 2017. United Kingdom. 102 (pp A202-A203).
23. May R, Thompson J. The Role of Pediatric Palliative Care in Complex Congenital Heart Disease: Three Illustrative Cases. *J Palliat Med*. 2017 Aug;
24. Mazwi ML, Henner N, Kirsch R. The role of palliative care in critical congenital heart disease. *Semin Perinatol*. 2017 Feb;

25. Pede CD, Agosto C, Tommasi V, Gregorio A, Benini F. Symptom management and psychological support for families are the cornerstones of end-of-life care for children with spinal muscular atrophy type 1. *Acta Paediatr.* 2017;
26. Pfeifer U, Gubler D, Bergstraesser E, Bassler D. Congenital malformations, palliative care and postnatal redirection to more intensive treatment - a review at a Swiss tertiary center. *J Matern-Fetal Neonatal Med Off J Eur Assoc Perinat Med Fed Asia Ocean Perinat Soc Int Soc Perinat Obstet.* 2017 Apr 16;1-6.
27. Porta NF. Palliative care approaches to neonates with chronic respiratory failure. *Semin Perinatol.* 2017 Feb;
28. Rodger E, Halkett C, Murdoch E. Neonatal palliative care-Alice's journey. *Palliat Med.* 2016 Jan 1;0:11th Palliative Care Congress. United Kingdom. Conference Start: 20160309. Conference End: 20160311. 30 (4) (pp S61).
29. Somanadhan S, Larkin PJ. The lived experience of parents of children with mucopolysaccharidosis (MPS). *Mol Genet Metab.* 2017 Jan 1;120(1):S125.

**Question 2: How do we engage in Advance Care Planning and Advance Directives discussions with children and families?**

30. Bateman LB and T NM and White, ML and Dure, LS and Clair, JM and Needham, BL. Physician Communication in Pediatric End-of-Life Care: A Simulation Study. *Am J Hosp Palliat Care.* 2016 Jan 1;33(10):935-41.
31. Bluebond-Langner M, Hargrave D, Henderson EM, Langner R. "I have to live with the decisions I make": Laying a foundation for decision making for children with life-limiting conditions and life-threatening illnesses. *Arch Child.* 2016 Dec;
32. Boss RD, Lemmon ME, Arnold RM, Donohue PK. Communicating prognosis with parents of critically ill infants: direct observation of clinician behaviors. *J Perinatol.* 2017;27(10):118.
33. Carter BS. Advance care planning: outpatient antenatal palliative care consultation. *Arch Child Fetal Neonatal Ed.* 2017 Jan;102(1):F3-F4. doi: 10.1136/archdischild-2016-311669. Epub 2016 Sep 29.
34. Dadiz R, Spear ML, Denney-Koelsch E. Teaching the Art of Difficult Family Conversations. *J Pain Symptom Manage.* 2016 Dec 23;
35. DeCoursey D, Silverman M, Oladunjoye A, Wolfe J. End-of-life care for children with medical complexity: Does advance care planning matter? *Crit Care Med.* 2016 Dec;44 (12 Supplement 1):213.
36. Delany C, Xafis V, Gillam L, Hughson JA, Hynson J, Wilkinson D. A good resource for parents, but will clinicians use it?: Evaluation of a resource for paediatric end-of-life decision making. *BMC Palliat Care.* 2017 Jan 25;16(1):12. doi: 10.1186/s12904-016-0177-5.
37. Henderson A, Young J, Herbert A, Bradford N, Pedersen LA. Preparing Pediatric Healthcare Professionals for End-of-Life Care Discussions: An Exploratory Study. *J Palliat Med.* 2017 Feb 10;
38. Lotz JD, Daxer M, Jox RJ, Borasio GD, Fuhrer M. "Hope for the best, prepare for the worst": A qualitative interview study on parents' needs and fears in pediatric advance care planning. *Palliat Med.* 2016 Nov 23;

**Question 3: How do we talk to children about their hopes, goals, and fears?**

39. Montreuil M, Carnevale FA. A concept analysis of children's agency within the health literature. *J Child Health Care.* 2016 Dec;20(4):503-11.
40. Bluebond-Langner M. *The private worlds of dying children.* Princeton, N.J: Princeton University Press; 1978. 282 p.

41. Aldridge J, Shimmon K, Miller M, Fraser LK, Wright B. "I can't tell my child they are dying". Helping parents have conversations with their child. *Arch Child Educ Pr Ed*. 2017 Jan 1;0.
42. Arruda-Colli MN, Weaver MS, Wiener L. Communication about Dying, Death, and Bereavement: A Systematic Review of Children's Literature. *J Palliat Med*. 2017 Jan 1;0.
43. Bates AT, Kearney JA. Understanding death with limited experience in life: dying children's and adolescents' understanding of their own terminal illness and death. *Curr Opin Support Palliat Care*. 2015 Mar;9(1):40–5.
44. Dallas RH, Kimmel A, Wilkins ML, Rana S, Garcia A, Cheng YI, et al. Acceptability of Family-Centered Advanced Care Planning for Adolescents With HIV. *Pediatrics* [Internet]. 2016;138(6). Available from: <http://pediatrics.aappublications.org/content/early/2016/10/30/peds.2016-1854>
45. Ekberg S, Danby S, Herbert A, Bradford NK, Yates P. Affording opportunities to discuss deterioration in paediatric palliative care consultations: a conversation analytic study. *BMJ Support Palliat Care*. 2017 Jan 1;0.
46. Hiscock A, Barclay S. "It's a hard conversation to have". Healthcare professionals' views concerning advance care discussions with young people affected by life-limiting neuromuscular diseases: an interview study. *BMJ Support Palliat Care*. 2017;19(001369):2017-001369.
47. Holland C, Nohavicka L, Aspel J, Hughes S. Children and young person advanced care plans in district general hospitals- who gets them? *Arch Dis Child*. 2017;Conference:Annual Conference of the Royal College of Paediatrics and Child Health, RCPCH 2017. United Kingdom. 102 (pp A207-A208).
48. Kazmerski TM, Weiner DJ, Matisko J, Schachner D, Lerch W, May C, et al. Advance care planning in adolescents with cystic fibrosis: A quality improvement project. *Pediatr Pulmonol*. 2016 Dec 1;51(12):1304–10.
49. Lyon ME, D'Angelo LJ, Dallas RH, Hinds PS, Garvie PA, Wilkins ML, et al. A randomized clinical trial of adolescents with HIV/AIDS: pediatric advance care planning. *AIDS Care*. 2017 Mar 30;1–10.
50. Rafferty KA, Hutton K, Heller S. "I Will Communicate With You, But Let Me Be In Control": Understanding How Parents Manage Private Information About Their Chronically Ill Children. *Health Commun*. 2017 Oct 26;1–10.
51. Wiener L, Rosenberg AR. Family-centred advanced care planning with adolescents living with HIV is perceived as important, helpful and meaningful. *Evid Based Nurs*. 2017;20(3):85. doi: 10.1136/eb-2017-102683. Epub 2017 Jun 13.

**Question 4: Are there prognostic markers for fragility and early death, especially in children with static encephalopathies such as severe neurological impairment due to hypoxia or structural brain dysgenesis?**

52. Alderton M, Pryde K. Child death and deterioration review group. *Arch Dis Child*. 2017;Conference:Annual Conference of the Royal College of Paediatrics and Child Health, RCPCH 2017. United Kingdom. 102 (pp A9).
53. Burke K, Coombes LH, Menezes A, Anderson AK. The "surprise" question in paediatric palliative care: A prospective cohort study. *Palliat Med*. 2017;1(269216317716061):0269216317716061.

**Question 5. Do our current treatments for pain work? What is the evidence for new assessment tools and treatments for the other symptoms children experience?**

54. Balfe JM, Booth A, Ritchie B. Problematic symptoms in children attending for short breaks at a children's hospice; Are we missing an opportunity for symptom assessment and management? *Arch Dis Child*. 2017;Conference:Annual Conference of the Royal College of Paediatrics and Child Health, RCPCH 2017. United Kingdom. 102 (pp A207).

55. Beecham E, Candy B, Howard R, McCulloch R, Laddie J, Rees H, et al. Pharmacological interventions for pain in children and adolescents with life-limiting conditions. *Cochrane Database Syst Rev* [Internet]. 2017;6(13). Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25768935>
56. Brown ML, Rojas E, Gouda S. A Mind-Body Approach to Pediatric Pain Management. *Children*. 2017;4(6):20.
57. Burns J, Jackson K, Sheehy KA, Finkel JC, Quezado ZM. The Use of Dexmedetomidine in Pediatric Palliative Care: A Preliminary Study. *J Palliat Med*. 2017 Feb 10;
58. Cif L, Coubes P. Historical developments in children's deep brain stimulation. *Eur J Paediatr Neurol*. 2017;21(1):109–17.
59. Friedrichsdorf SJ. Four steps to eliminate or reduce pain in children caused by needles (part 1). *Pain Manag*. 2017;7(2):89–94.
60. Friedrichsdorf SJ. Multimodal pediatric pain management (part 2). *Pain Manag*. 2017 Jan 20;20(10):mt-2016.
61. Friedrichsdorf SJ, Kohen DP. Integration of hypnosis into pediatric palliative care. *Ann Palliat Med*. 2017;
62. Friedrichsdorf SJ, Postier AC, Andrews GS, Hamre KE, Steele R, Siden H. Pain reporting and analgesia management in 270 children with a progressive neurologic, metabolic or chromosomally based condition with impairment of the central nervous system: cross-sectional, baseline results from an observational, longitudinal study. *J Pain Res*. 2017;10:1841–52.
63. Harris N, Baba M, Berringer A, Mellor C, Rogers R, Taylor K, et al. Seizure management in end of life care for children. *Dev Med Child Neurol*. 2017 Jan;
64. Hauer J, Houtrow AJ. Pain Assessment and Treatment in Children with Significant Impairment of the Central Nervous System. *Pediatrics*. 2017; 139(6).
65. Jaiswal N, Singh M, Agarwal A, Thumburu KK. Palliative drug treatments for breathlessness in cystic fibrosis. *Cochrane Database Syst Rev*. 2017 Aug 10;8:Cd011855.
66. Jamieson L, Wong ICK, Craig F, Christiansen N, Brombley K, Tuleu C, et al. Palliative medicines for children – a new frontier in paediatric research. *J Pharm Pharmacol*. 2017 Apr 1;69(4):377–83.
67. Knops RRG, Kremer LCM, Verhagen AAE. Paediatric palliative care: Recommendations for treatment of symptoms in the Netherlands Palliative care in other conditions. *BMC Palliat Care*[Internet]. 2015;14(1). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4634793/>
67. Ringuier B, Troussier F, Boussicault G, Chapotte C, Rachieru P. [Non invasive ventilation and pediatric palliative care. A French survey]. *Arch Pediatr*. 2017;24(8):712–719. doi: 10.1016/j.arcped.2017.05.007. Epub 2017 Jun 28.
68. Thrane SE, Maurer SH, Ren D, Danford CA, Cohen SM. Reiki Therapy for Symptom Management in Children Receiving Palliative Care: A Pilot Study. *Am J Hosp Palliat Care*. 2017 May;34(4):373–9.
69. Weaver M. Healing Touch: Positively Sharing Energy in a Pediatric Hospital. *J Pain Symptom Manage*. 2017 Jan;4(16):31241–6.

#### **Question 6. Who are the children that do and those that should receive pediatric palliative care?**

70. Feudtner C, Christakis DA, Connell FA. Pediatric Deaths Attributable to Complex Chronic Conditions: A Population-Based Study of Washington State, 1980–1997. *Pediatrics*. 2000 Jul 1;106(Supplement 1):205–9.
71. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, Koepsell TD. Deaths Attributed to Pediatric Complex Chronic Conditions: National Trends and Implications for Supportive Care Services. *PEDIATRICS*. 2001 Jun 1;107(6):e99–e99.

72. Alderton M, Pryde K. Child death and deterioration review group. Arch Dis Child. 2017;Conference:Annual Conference of the Royal College of Paediatrics and Child Health, RCPCH 2017. United Kingdom. 102 (pp A9).
73. Ananth P, Melvin P, Feudtner C, Wolfe J, Berry JG. Hospital use in the last year of life for children with life-threatening complex chronic conditions. Pediatrics. 2015;136(5):938–46.
74. Boyden JY, Curley MAQ, Deatrck JA, Ersek M. Factors Associated with Use of U.S. Community-Based Palliative Care for Children with Life-Limiting or Life-Threatening Illnesses and Their Families: An Integrative Review. J Pain Symptom Manage. 2017 Aug 11;
75. Du Pont-Thibodeau A, Barrington K, Taillefer C, Janvier A. Changes in perinatal hospital deaths occurring outside the neonatal intensive care unit over a decade. Acta Paediatr Oslo Nor 1992. 2017 Apr 23;
76. Fraser LK, Fleming S, Parslow R. Changing place of death in children who died after discharge from paediatric intensive care units: A national, data linkage study. Palliat Med. 2017;269216317709711.
77. Fraser LK, Parslow R. Children with life-limiting conditions in paediatric intensive care units: a national cohort, data linkage study. Arch Child. 2017;13(312638):2017–312638.
78. García-Salido A, Santos-Herranz P, Puertas-Martín V, García-Teresa MÁ, Martino-Alba R, Serrano-González A. [Retrospective study of children referred from paediatric intensive care to palliative care: Why and for what]. An Pediatr Barc Spain 2003. 2017 Apr 17;
79. Gaucher N, Humbert N, Gauvin F. What do we know about pediatric palliative care patients who consult the emergency department? J Pain Symptom Manage. 2016 Dec;52 (6):e16.
80. Hakanson C, Ohlen J, Kreicbergs U, Cardenas-Turanzas M, Wilson DM, Loucka M, et al. Place of death of children with complex chronic conditions: cross-national study of 11 countries. Eur J Pediatr [Internet]. 2017; Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed18b&AN=614021353>
81. Jarvis SW, Fraser LK. Comparing routine inpatient data and death records as a means of identifying children and young people with life limiting conditions. Palliat Med [Internet]. 2017; Available from: [https://pure.york.ac.uk/portal/en/publications/comparing-routine-inpatient-data-and-death-records-as-a-means-of-identifying-children-and-young-people-with-life-limiting-conditions\(0ac8dc72-669c-4300-9250-c7118329a31d\).html](https://pure.york.ac.uk/portal/en/publications/comparing-routine-inpatient-data-and-death-records-as-a-means-of-identifying-children-and-young-people-with-life-limiting-conditions(0ac8dc72-669c-4300-9250-c7118329a31d).html)
82. Johnston EE, Alvarez E, Saynina O, Sanders L, Bhatia S, Chamberlain LJ. Disparities in the intensity of end-of-life care for children with cancer. Pediatrics [Internet]. 2017;140(4). Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emexb&AN=618636662>
83. Kassam A, Sutradhar R, Widger K, Rapoport A, Pole JD, Nelson K, et al. Predictors of and Trends in High-Intensity End-of-Life Care Among Children With Cancer: A Population-Based Study Using Health Services Data. J Clin Oncol. 2017 Jan 10;35(2):236–42.
84. Lindley LC. Multiple Complex Chronic Conditions and Pediatric Hospice Utilization among California Medicaid Beneficiaries, 2007-2010. J Palliat Med. 2017 Jan 1;20(3):241–6.
85. Lindley LC, Colman MB, Meadows JT Jr. Children with intellectual disability and hospice utilization. J Hosp Palliat Nurs. 2017 Jan 1;19(1):28–33.
86. Murphy NA, Clark EB. Children with Complex Medical Conditions: an Under-Recognized Driver of the Pediatric Cost Crisis. Curr Treat Options Pediatr. 2016 Dec;2(4):289–95.

87. Thrane SE, Maurer SH, Cohen SM, May C, Sereika SM. Pediatric Palliative Care: A Five-Year Retrospective Chart Review Study. *J Palliat Med.* 2017;6(10).
88. Villanueva G, Murphy MS, Vickers D, Harrop E, Dworzynski K. End of life care for infants, children and young people with life limiting conditions: summary of NICE guidance. *BMJ.* 2016 Dec;355:i6385.
89. Widger K, Davies D, Dauost L, Liben S, Rapoport A, Gregoire MC, et al. Not there yet: Pediatric palliative care in Canada 2002-2012. *J Pain Symptom Manage.* 2016 Dec;52 (6):e49.
90. Widger K, Seow H, Rapoport A, Chalifoux M, Tanuseputro P. Children's End-of-Life Health Care Use and Cost. *Pediatrics.* 2017 Jan 1;0.
91. Widger K, Vadeboncoeur C, Zelcer S, Liu Y, Kassam A, Sutradhar R, et al. The Validity of Using Health Administrative Data to Identify the Involvement of Specialized Pediatric Palliative Care Teams in Children with Cancer in Ontario, Canada. *J Palliat Med.* 2017 Nov;20(11):1210–6.
- Question 7. What are the outcomes of pediatric palliative care of importance, and how do we structure services to achieve these outcomes?**
92. Aiyelaagbe E, Scott RE, Holmes V, Lane E, Heazell AEP. Assessing the quality of bereavement care after perinatal death: development and piloting of a questionnaire to assess parents' experiences. *J Obstet Gynaecol.* 2017;21:1–6.
93. Bogetz JF, Friebert S. Defining Success in Pediatric Palliative Care while Tackling the Quadruple Aim. *J Palliat Med.* 2017;20(2):116–9.
94. Coombes LH, Wiseman T, Lucas G, Sangha A, Murtagh FEM. Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use. *Palliat Med.* 2016;30(10):935–49.
95. Duc J, Widger K, Johnston K, Rapoport A, Siden H, Feudtner C, et al. Identifying indicators of quality pediatric palliative care: A systematic review. *J Pain Symptom Manage.* 2016 Dec;52 (6):e133–4.
96. Harding R, Wolfe J, Baker JN. Outcome Measurement for Children and Young People. *J Palliat Med.* 2017 Jan 10;10(10).
97. Hill DL, Miller VA, Hexem KR, Carroll KW, Faerber JA, Kang T, et al. Problems and hopes perceived by mothers, fathers and physicians of children receiving palliative care. *Health Expect Int J Public Particip Health Care Health Policy.* 1052;18(5):1052–65.
98. Johnston EE, Rosenberg AR, Kamal AH. Pediatric-Specific End-of-Life Care Quality Measures: An Unmet Need of a Vulnerable Population. *J Oncol Pr.* 2017;Jop2017021766.
99. Kaye EC, Abramson ZR, Snaman JM, Friebert SE, Baker JN. Productivity in Pediatric Palliative Care: Measuring and Monitoring an Elusive Metric. *J Pain Symptom Manage.* 2017 Jan;3(16):31225–8.
100. Lemmon ME, Donohue PK, Parkinson C, Northington FJ, Boss RD. Parent experience of neonatal encephalopathy: The need for family-centered outcomes. *J Child Neurol.* 2017 Jan 1;32(3):286–92.
101. Lindley LC, Keim-Malpass J. Quality of paediatric hospice care for children with and without multiple complex chronic conditions. *Int J Palliat Nurs.* 2017;23(5):230–7.
102. Mitchell S, Morris A, Bennett K, Sajid L, Dale J. Specialist paediatric palliative care services: what are the benefits? *Arch Dis Child.* 2017 Apr 4;
103. Thienprayoon R, Mark MSJ, Grosseohme D. Provider-Prioritized Domains of Quality in Pediatric Home-Based Hospice and Palliative Care: A Study of the Ohio Pediatric Palliative Care and End-of-Life Network. *J Palliat Med.* 2017;

104. Weaver MS, Darnall C, Bace S, Vail C, MacFadyen A, Wichman C. Trending Longitudinal Agreement between Parent and Child Perceptions of Quality of Life for Pediatric Palliative Care Patients. *Child Basel*. 2017 Aug;4(8).

105. Wool C, Kain VJ, Mendes J, Carter BS. Quality predictors of parental satisfaction after birth of infants with life-limiting conditions. *Acta Paediatr*. 2017;11(10):13980.

**Question 8. Do we understand parental grief and bereavement sufficiently to make strong recommendations regarding service provision?**

106. Aiyelaagbe E, Scott RE, Holmes V, Lane E, Heazell AEP. Assessing the quality of bereavement care after perinatal death: development and piloting of a questionnaire to assess parents' experiences. *J Obstet Gynaecol*. 2017;21:1–6.

107. Albuquerque S, Buyukcan-Tetik A, Stroebe MS, Schut HAW, Narciso I, Pereira M, et al. Meaning and coping orientation of bereaved parents: Individual and dyadic processes. *PLoS One*. 2017;12(6):e0178861. doi: 10.1371/journal.pone.0178861. eCollection 2017.

108. Albuquerque S, Narciso I, Pereira M. Posttraumatic Growth in Bereaved Parents: A Multidimensional Model of Associated Factors. *Psychol Trauma*. 2017;6(10).

109. Colwell P. Building confidence in neonatal bereavement: The use of simulation as an innovative educational approach. *J Neonatal Nurs*. 2017 Apr;23(2):65–74.

110. Denhup CY. A New State of Being The Lived Experience of Parental Bereavement. *Omega Westport*. 2017;74(3):345–360. doi: 10.1177/0030222815598455. Epub 2016 Aug 3.

111. Dias N, Docherty S, Brandon D. Parental Bereavement: Looking beyond Grief. *Death Stud*. 2017 Jan 10;10(10):1279239.

112. Dyregrov A, Dyregrov K. Parents' Perception of Their Relationship Following the Loss of a Child. *Omega J Death Dying*. 2017;76(1):35–52.

113. Inati V, Matic M, Phillips C, Maconachie N, Vanderhook F, Kent AL. A survey of the experiences of families with bereavement support services following a perinatal loss. *Aust N Z J Obstet Gynaecol*. 2017;28(10):12661.

114. Lopes BG, Borges PKD, Grden CRB, Coradassi CE, Sales CD, Damasceno NFP. Maternal mourning: pain and coping with the loss of a baby. *Rev Rede Enferm Nordeste*. 2017 May;18(3):307–13.

115. Masterson MP, Hurley KE, Zaider T, Corner G, Schuler T, Kissane DW. Psychosocial Health Outcomes for Family Caregivers Following the First Year of Bereavement. *Death Stud*. 2015;39(10):573–8.

116. Snaman J, Levine D, Baker J. Empowering bereaved parents in the development of a comprehensive bereavement program. *J Pain Symptom Manage*. 2016 Feb;51 (2):387–8.

**Question 9. What is, and will be, the impact of assisted death in children on pediatric palliative care?**

117. Birchley G, Gooberman-Hill R, Deans Z, Fraser J, Huxtable R. "Best interests" in paediatric intensive care: an empirical ethics study. *Arch Dis Child [Internet]*. 2017 Mar 10 [cited 2017 May 1]; Available from: <http://adc.bmj.com/content/early/2017/04/13/archdischild-2016-312076>

118. Bolt EE, Flens EQ, Pasman HRW, Willems D, Onwuteaka-Philipsen BD. Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide. *Acta Paediatr*. 2017 Apr;106(4):668–75.

119. Carter BS. Why Palliative Care for Children is Preferable to Euthanasia. *Am J Hosp Palliat Care*. 2016 Feb;33(1):5–7.

120. Lemmens C. End-of-life decisions and minors: do minors have the right to refuse life preserving medical treatment? A comparative study. *Med Law*. 2009 Jan 1;28(3):479–97.

**Question 10. What are the fundamental elements of palliative care that should be applied in every setting and what are the means to provide that in less-well resourced countries?**

121. Celiker MY, Pagnarith Y, Akao K, Sophearin D, Sorn S. Pediatric Palliative Care Initiative in Cambodia. *Front Public Health*. 2017;5:185.

122. Chong LA, Khalid F, Khoo TB, Teh SH, Kuan GL, Abdul Manaf AM, et al. Clinical spectrum of children receiving palliative care in Malaysian Hospitals. *Med J Malaysia*. 2017;72(1):32–6.

123. Chong L, Abdullah A. Community Palliative Care Nurses' Challenges and Coping Strategies on Delivering Home-Based Pediatric Palliative Care. *Am J Hosp Palliat Med*. 2017;34(2):125–31.

124. Pereira I, Koziol S, Mauvezin J, Notejane M, Bernad  M. Directives of adequacy of the therapeutic effort in children. Experience of the Pediatric Palliative Care Unit of Pereira Rossell Hospital Center (2009-2015). *Rev Medica Urug*. 2017;33(1):24–33.

125. Rojas N, Rosas A, Araya E, Varela J, Lopez P, Gallastegui A. Pediatric palliative care (PPC) access in Chile: Private practice health insurance law implementation. *Pediatr Blood Cancer*. 2017;Conference:30th Annual Meeting of the American Society of Pediatric Hematology/Oncology, ASPHO 2017. Canada. 64 (pp S66).

126. Were P. Challenges of managing children with life limiting conditions in a county hospital in western Kenya. *Support Care Cancer*. 2017;Conference:2017–International MASCC/ISOO Symposium: Supportive Care in Cancer. United States. 25 (2 Supplement 1) (pp S183–S184).

**A MESSAGE FROM THE CHIPPS CO-CHAIRS**

*Holly Davis, MS, APRN*  
**Hospice Executive Director**  
**St. Francis Healthcare System**  
**Honolulu, HI**  
[HDavis@stfrancishawaii.org](mailto:HDavis@stfrancishawaii.org)

*Marilyn A. Fisher, M.D., M.S.*  
**Associate Professor of Pediatrics**  
**Albany Medical College**  
**Albany, NY**  
[fisherm@mail.amc.edu](mailto:fisherm@mail.amc.edu)

This issue marks the 50th issue of the National Hospice and Palliative Care Organization's (NHPCO) Children's Project on Hospice/Palliative Services (ChiPPS) e-journal. So much great work and progress has been made during this time; all the trainings and education offered thru this quarterly newsletter; providing our communities with necessary information about providing care to children who are living with a life-limiting or life-threatening condition, and supporting their families.

The electronic journal itself is edited and written by a number of diverse individuals with special insight into the world of pediatric hospice and palliative care, ranging from families to physicians and nurses, to school teachers and allied health care professionals, such as music therapists, chaplains, homeopathic practitioners, and social workers, and so many more contributors.

In addition to the electronic journal, over the years, ChiPPS has provided other learning opportunities for NHPCO members caring for children - from pediatric workshops, pediatric networking meetings, clinical tracks at conferences, and pediatric intensives. For the past year, web-based resources have been made available monthly thru an on-line educational resource, which incorporates a succinctly-written article combined with a PowerPoint slide presentation designed to facilitate health care professionals in teaching others about particular issues in pediatric hospice and palliative care. ChiPPS is also currently preparing a community based “how to” resource manual to help guide and assist hospice agencies caring for children, or hospice agencies considering a starting a pediatric program, to organize and structure a program that is child- and family-centered, while also meeting financial demands and needs.

The NHPCO ChiPPS Advisory Council mirrors the importance of multidisciplinary collaboration in hospice care as evidenced by in its council membership. The membership is comprised of a very diverse group of enthusiastic, caring, dedicated, and talented individuals from locations around the United States and disciplines. The Council is comprised of physicians, nurses, social workers, music therapists, child life specialists, educators, and school teachers from community based programs, academic institutions, and acute care settings, in both rural and urban locations. The membership covers the whole United States from New York to Florida, Kansas, California and Hawaii. We have come together in hopes of concentrating our efforts to better educate the care providers of this deserving pediatric patient population.

We would like to take this opportunity to thank each of the past and current NHPCO ChiPPS Advisory Council members for all their hard work in the field of pediatric hospice and palliative care. THANK YOU!

We applaud our current ChiPPS Advisory Council members:

- |                       |                         |                                |
|-----------------------|-------------------------|--------------------------------|
| ■ Stephanie Allen, OH | ■ Melissa Hunt, AL      | ■ Christy Torkildson, CA       |
| ■ Laurie Barbaro, VA  | ■ Jennifer Mangers, IL  | ■ Yelena Zatulovsky, IL        |
| ■ Jody Chrastek, MN   | ■ Carolyn McCardell, PA | ■ Zinnia Harrison, NHPCO       |
| ■ Kathy Davis, KS     | ■ Jacki Naradone, FL    | ■ Hope Fost, NHPCO             |
| ■ Ann Fitzsimons, MI  | ■ Diane Parker, SC      | ■ Holly Davis, Co-Chair, HI    |
| ■ Lily Gillmor, NC    | ■ Elizabeth Rocha, MI   | ■ Marilyn Fisher, Co-Chair, NY |
| ■ Betsy Hawley, PA    | ■ Shayna Stiles, CA     |                                |
| ■ Jennifer Holler, FL | ■ Liz Sumner, CA        |                                |

In looking forward, ChiPPS will continue to seek new, innovative methods to furnish care providers with education and support, and to improve access to pediatric hospice and palliative care services through web-based trainings, electronic resources, and advocacy to those providing care to children living with life-threatening and life-limiting conditions.

## THANK YOU FOR MANY SIGNIFICANT CONTRIBUTIONS

*Edo Banach, JD*

**NHPCO President and CEO**

[ebanach@nhpco.org](mailto:ebanach@nhpco.org)

I am proud to share the 50th issue of the ChiPPS e-journal with the field and I extend my deepest appreciation to the many people who make each issue possible. Over the past several years, we have featured hundreds of articles by dozens of experts and thought-leaders from the pediatric palliative and hospice care field. We have also included contributions from family members who have faced the overwhelming loss of a beloved child. And members of our ChiPPS E-Journal Workgroup have given of their time, talent, and insight to make the e-journal a valuable resource offered free-of-charge to anyone interested in this important area.

For those of you reading this article in the ChiPPS e-journal, there is no need for me to tell you how essential it is to have members of the IDT skilled in caring for the unique needs of young people facing serious and life-limiting illness and being able to appropriately care for grieving families. The death of a child is surely one of the great challenges that those in our field face; yet, it is a reality that young people do die and over the years, NHPCO has done its best to provide resources, education, and opportunities to advocate on behalf of pediatric care.

Our Children's Project on Palliative/Hospice Services began with a two-day meeting in Dallas in November 1998. So as we celebrate this milestone issue of the e-journal, we are just about to mark the 20th anniversary of ChiPPS.

Since 1998, the accomplishments of ChiPPS have played a vital role in shaping the entire national pediatric palliative care and hospice field and the written word has been a significant part of these efforts. Let me acknowledge just a few of the key accomplishments of NHPCO's Children's Project on Palliative/Hospice Services:

- Issued the ground-breaking report, *A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions*, in 2001.
- Published the professional resources: *Compendium of Pediatric Palliative Care*; *Pediatric Palliative Care Educational Curriculum*; and *Caring for Kids: How to Develop a Home-Based Support Program*.
- Developed, field-tested, and published the first national standards document, *Pediatric Palliative Care Standards of Practice for Hospice Programs*.
- Released the report NHPCO's *Facts and Figures: Pediatric Palliative & Hospice Care in America*.
- Contributed to NHPCO's work with the District of Columbia Pediatric Palliative Care Collaborative to create the *Concurrent Care for Children Implementation Toolkit*, which details information on the options available to states implementing Section 2302 of the Patient Protection and Affordable Care Act signed into law on March 23, 2010.
- Supported NHPCO in the creation and sponsorship of "Linking Hands, Linking Hearts," the first National Conference on Pediatric Palliative and Hospice Care in 2004, held in Dearborn, Michigan.
- Served as advisors for the PBS documentary, *Lion in the House*, in 2006.
- Developed a two-day pediatric intensive that was offered before several of NHPCO's Clinical Team Conferences beginning in 2008.
- Acted as advisors for the NHPCO national initiative, Partnership for Children.
- Served as advisor to NHPCO's consumer engagement initiative Caring Connections (now known as NHPCO's CaringInfo) in the development of educational brochures for families of seriously-ill children.
- Contributed to the NHPCO library of Palliative Care Issue Briefs to include briefs on pediatric palliative and hospice care.
- Developed a series of online training modules on pediatric palliative care geared for physicians, nurses, counselors, and social workers that were released in 2013 via NHPCO's E-OL.

Many of these noted achievements were crafted with the goal of addressing barriers to pediatric palliative and hospice care and to increasing access. Ensuring that an organized method for delivering competent, compassionate, and consistent care to children and their families coping with chronic, complex, and/or life-threatening conditions guided the work of NHPCO and ChiPPS over the past 20 years and I am proud of our contributions.

More remains to be done. While we celebrated the inclusion of concurrent care for children that was included in the Affordable Care Act, barriers remain. Physicians must still certify that a child is within the last six months of life, should the disease run its normal course, in order to access care. Additionally, children who qualify for the benefit remain limited to the existing array of

Medicaid hospice services and other existing Medicaid services covered by the state of residence; however, a child may be simultaneously enrolled in other programs that provide supplemental services such as home and community-based service (HCBS) waivers.

We can learn from states that have implemented options to increase access. Some states have created advocacy groups and coalitions that help facilitate the ongoing work needed to enhance the current landscape of pediatric palliative and hospice care. Ongoing data collection will continue to serve in the shared mission to address unmet needs of medically fragile children. We must continue to collaborate amongst our provider community while engaging with partners and key stakeholders outside of the field.

The hospice community successfully flourished based on the willingness to collaborate, the willingness to share lessons learned, and the understanding that we must speak with a unified voice. I am confident that the field will continue to move forward, inspired by our past accomplishments.

On behalf of NHPCO, our board, and the hospice and palliative care community, let me offer my heartfelt thanks to all those working to advance care for young people and families in need. Particularly, as we release the 50th anniversary of the e-journal, I thank the members of ChiPPS E-Journal Workgroup for their dedication and commitment to improving the lives of seriously-ill children and their families.

## ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

### 1. NHPCO PALLIATIVE CARE ONLINE RESOURCES:

NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://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

### 2. 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](http://www.caringinfo.org)

- When Your Child is in Pain
- Talking With Your Child About His or Her Illness
- Talking to Your Child's Doctor: When Your Child Has a Serious Illness
- When a Child Dies: A Guide for Family and Friends
- Helping Children Cope with the Loss of a Loved One

**NHPCO's Palliative Care Resource Series** now includes pediatric palliative resources such as:

- 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
- 'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning
- 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

**Center to Advance Palliative Care:** Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.

- **Pediatric Palliative Care Survey in the CAPC National Registry:** Submit your program data now to generate individualized performance reports on program structure and operations, as well as comparisons to other pediatric palliative care programs. CAPC membership is not required.

■ **The Pediatric Palliative Care Field Guide:** A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.

■ **The CAPC Pediatric Palliative Care Toolkit:** A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.

**“A Perinatal Pathway for Babies with Palliative Care Needs”** from Together for Short Lives in the U.K., developed in conjunction with ethicists and clinicians working across obstetrics, antenatal and neonatal care, and children’s palliative care. Full pathway available for free download via this press release and links here: <http://www.togetherforshortlives.org.uk/news/11605-together-for-short-lives-launches-vital-resource>

**Three Years ago Holland Bloorview Kids Rehabilitation Hospital launched the [Chronic Pain Assessment Toolbox for Children with Disabilities](#).** The Toolbox has received over 6000 downloads to date! Since then three eLearning modules have been developed. The modules will introduce you to:

1. Chronic pain in children with cerebral palsy and the development of the Toolbox
2. The sections of the Toolbox and how to start with based on your needs
3. A case study of a complex patient from one of our nurse practitioners, and how a chronic pain assessment tool supported her clinical examination.

Check them out here: <http://hollandbloorview.ca/Toolbox>

### 3. PEDIATRIC HOSPICE AND PALLIATIVE CARE TRAINING:

**2018 Pediatric Webinar Series:** The 2018 Pediatric Webinar Series is presented in collaboration with the Pennsylvania’s Pediatric Palliative Care Coalition (PPCC) and Greater Illinois Pediatric Palliative Care Coalition (GIPPCC).

In times of illness and in health, the role of spirituality can be a crucial coping mechanism, even in young children. For a child facing a life-threatening illness, the experience can raise profound spiritual questions of meaning and connection. Spirituality may influence how they experience their illness and play a crucial role in decision-making.

In this webinar, we will explore children’s spiritual development and needs, both in terms of theology and practical application for integrating spiritual support for children into your own medical practice.

- March 20th - Increasing Adult-Trained Nurses’ Confidence and Competencies to Care for Children with Jody Chrastek, RN and Diane Knust, LCSW
- April 17th - Perinatal Hospice with David Munson, MD
- May 17th - Concurrent Care with Shayna Stiles

**Perinatal Palliative Care Symposium:** This full day educational symposium is designed for regional health care providers who share an interest in perinatal palliative care. The topics covered in this symposium will include cultural support, support of the family as a unit, and the intersection of ethics in perinatal palliative care.

Friday, March 16, 2018

Newark, Delaware

Registration MUST be made online by [clicking here](#).

**Pediatric Hospice and Palliative Care: Advances and Innovations (Pedi-Innovate):** This summer pediatrics course will be a forum for interdisciplinary healthcare professionals and others with an interest in pediatric palliative care to deepen their knowledge and understanding of this nascent and rapidly-evolving field.

Through this course, we aim to advance pediatrics in hospice and palliative care for children with serious illness, thereby optimizing their quality of life, regardless of treatment course or illness trajectory. Learners will improve their knowledge, competence, and change their performance, leading over time to enhanced patient outcomes.

August 9-11, 2018

Minneapolis, MN

<http://aahpm.org/meetings/pediatrics-course>

#### 4. JOURNAL / NEWS ARTICLES

**Meet the Woman Helping Terminally Ill Kids Realize Their Movie-Making Dreams:** “A nonprofit organization that connects children and teens battling terminal illnesses with Hollywood heavy-hitters, helping young patients with limited time to write, produce and premiere their own movies.” Read more [here](#)

**Minnesota's first freestanding pediatric hospice home celebrates grand opening:** “When the children and their families showed up for a special preview open house last Saturday, Katie Lindenfelser felt that her dream of creating Crescent Cove, Minnesota's first freestanding pediatric hospice, was finally coming true.” Read more [here](#)

**5. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL.** For upcoming E-Journal issues, we plan to address issues related to: Hospice and Bereavement for Crisis Situations, and Caring for Diverse Families and Populations. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at [ctorkildson@mail.cho.org](mailto:ctorkildson@mail.cho.org) or [christytork@gmail.com](mailto:christytork@gmail.com); or Chuck Corr at [ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com). We will work with you!

**6. READER'S CORNER.** Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at [christytork@gmail.com](mailto:christytork@gmail.com).

**7. SUPPORT THIS WORK.** Funding through the National Hospice Foundation (NHF) for national pediatric initiatives has played and continues to play a vital role in shaping the entire pediatric palliative care and hospice field. Donate online to support this important work. Questions on how you can support the work of pediatric palliative care, contact Sarah Meltzer at [smeltzer@nationalhospicefoundation.org](mailto:smeltzer@nationalhospicefoundation.org).

# ChiPPS E-Journal

***Children's Project on Palliative/Hospice Services***

Released in collaboration with the National Hospice and Palliative Care Organization

1731 King Street, Alexandria VA 22314

1-800-646-6460

[www.nhpco.org/chipps-e-journal](http://www.nhpco.org/chipps-e-journal)

National Hospice and Palliative Care  
Organization

