



E-NEWS

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and Maureen Horgan, LICSW*

Issue Topic: Differences between Pediatric Hospice and Pediatric Palliative Care

Welcome to the thirty-second issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some aspects of differences between pediatric hospice care and pediatric palliative care. Our primary goal in this issue is to promote reflection on these two closely-related modes of care. At the same time, we also want to contribute to a better understanding of what it is like to offer in any format care for children, adolescents, and their family members who are coping with life-threatening or life-limiting conditions especially in the face of end-of-life issues. We hope that the articles in this issue and the comments they make about this overall field of care will encourage greater recognition of the issues involved and of the care needed in these circumstances.

Note that while articles in each issue of this newsletter are mainly organized around a specific subject matter, we often include some articles outside that specific focus because of their intrinsic interest. We believe you will find one or two impressive articles of this latter type in this issue.

This newsletter 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 NHPCO's E-newsletter Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpc.org/pediatrics.

Comments about the activities of ChiPPS, its E-newsletter Workgroup, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at christytork@gmail.com or Maureen at horgan.maureen@gmail.com.



Issue #32: Differences between Pediatric Hospice and Pediatric Palliative Care

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

Acronyms

p. 4

Scott Newport

A frequent contributor of poetry to the ChiPPS e-Newsletter, Scott adopts an essay format in this piece to present a wonderful illustration of the challenges and teamwork needed to care for a medically fragile child and how easily it can be to lose focus on the goals of such care.

Mackenzie's Story as Told by Her Mother, Tara

p. 6

Connie Bergh, MSH, RN, CHPPN

Connie shares an interview with Mackenzie's mom, Tara. Mackenzie is a child who was not supposed to live, but actually graduated hospice and is now being served by a palliative care team. Tara shares tips about what is and is not helpful in navigating the challenges with a medically fragile child.

Frequently Asked Questions: What are the Differences between Pediatric Hospice and Palliative Care?

p. 8

Donna Armstrong, MSW, CSW

Donna provides a brief overview of some key differences between pediatric hospice and pediatric palliative care.

Pediatric Palliative vs. Hospice Care Defined: Are They the Same? Different? Does It Matter?

p. 11

Ann Fitzsimons, BS & MBA

Ann furthers the discussion of the central topic of this issue and, in the course of doing so, provides a lot of "food for thought." We would all appreciate learning what your thoughts are about Ann's observations.

Billing for Pediatric Hospice/Palliative Care

p. 16

Kelly Cronin Komatz, MD, MPH, FAAP, FAAHPM

Kelly provides an overview of billing for inpatient and outpatient palliative care along with suggested codes and time frames. A practical how to!

Developing a Pediatric Palliative Care Program in Westchester County, New York

p. 18

Nancy Caputi, RN

Nancy relates how her adult-oriented organization developed a pediatric palliative care program. There are many lessons that can be used across settings in this piece!

How Do Palliative Care Physicians Feel about Providing Care for Pediatric Patients?

p. 20

Adam Rapoport, MD, FRCPC, MHSc

Adam is one of the primary investigators in a study focused on this topic. His article provides background and findings that help illustrate the continued challenges in access to care for children. He provides excellent insights and suggestions, as well as highlighting the need for further research. We believe this is a must read!

"Oh My Goodness, They Want Us to Take a Child"

p. 23

Christy Torkildson, RN, PHN, MSN, PhDc, & Joseph C. Torkildson, MD, MBA

In this piece, the authors suggest a strategy that can guide hospice and palliative care providers in caring for pediatric patients even when they have little prior experience in offering such care. We believe this is another essential article for readers!

Items of Interest

p. 26

ChiPPS customarily shares items that may be of interest to our readers.



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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-News Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.



ACRONYMS

Scott Newport

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Evan was a complicated kid with more than one diagnosis including a DNR order. For those who may not know what that stands for DNR is an acronym for Do Not Resuscitate. Evan's heart was so sick they told us if it ever stopped it could get very ugly. They left it in our hands to make a decision no parent should ever have to embrace.

Our family was back at C.S. Mott Children's Hospital at the University of Michigan and Evan was going to have a simple, surgical procedure revising his trach site. Evan was ventilator dependent requiring a small hole in his chubby neck allowing him to breathe.

Our nurses at home had been having difficulties with weekly trach changes and were afraid to do the procedure alone. Penni and I learned to deal with the challenge but were not always around to help. You know with work and another son we had to live life as normal as possible.

The morning of the procedure Evan spiked a fever and everyone soon agreed it would be impossible to continue.

"Well I guess we should just head back home," I said during morning rounds.

The resident looked at me and said, "We need to do some tests first to make sure we know what we are battling."

As the shuffling team left the room I wondered how long we would be here. When Evan was born four years earlier at Mott we endured 252 days in the PICU leaving with a diagnosis of, "Children like Evan usually don't live past the age of two."

I immediately called my parents and a few other friends and told them the news of the canceled surgery and not to come. My next call was to Nancy, one of Evan's cardiologists. She had always been an advocate for us and also had become a good friend. She asked me what I thought and I said, "Well you know Evan, no telling, but Penni and I are not too worried and hope to get out of here soon."

Nancy told me to call her tomorrow with an update.

The next morning at rounds there were still no clear answers but Evan still had a fever, required a bit more oxygen, and no one seemed to know what was going on. Those wandering eyes of the crew didn't even have to speak for me to figure that out.

That night one of our homecare nurses came up to see us and took about an hour to rock Evan to sleep. As we sat in the four bed ventilator ward we discussed that Evan should be home where we could take care of him. If he did end up getting really sick and looked like he may die we wanted him home.

The next morning got a bit more frustrating, as now, even the attending was not sure what Evan had and wanted to do more tests. Again I brought up the going home issue but they seemed to think it was impossible.



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Starting to get angry I called Nancy. Hey Nancy we want to go home but no one is listening. She then said something I will never forget and was able to use again and again for the next few years on our families behalf. She said, "Scott, tomorrow at rounds ask them this....."

Well tomorrow came and as it was my turn to speak I said, "Hey guys, what are you doing here in the hospital we couldn't do at home?"

As you can imagine everyone looked at each other and then the attending said, "Well Scott and Penni, I'm sure you guys are probably better than us at taking care of your son, let's see if we can't get you discharged this afternoon."

It was great and even our bedside nurse said she had learned something that day also and giggled as she started to do her morning work with Penni to get Evan ready to go home.

And yes as soon as the team of residents, fellows, a respiratory therapist, social worker, charge nurse and the attending left I called Nancy. I could almost see her smile through the phone as I thanked her and thanked her for all she had done for our family for the past four years. She just came back with, "You know Scott I have always thought of your family as special and will always be there for you guys."

Remember in the beginning when I told you about Evan's DNR status. Our family has an acronym for that, too. In fact the day after we had to sign that order when Evan was about eleven months old I took a piece of hospital stationary (paper towel) and a blue marker from the nurses' station and had this posted on his PICU glass door for all who entered our world.

Do

Not

Retreat

Not everyone who passed that sign back then, "got it," but almost all of them if I asked today would agree that was a good thing, forming them to be better partners with patients and families.



MACKENZIE'S STORY AS TOLD BY HER MOTHER, TARA

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Community PedsCare is a pediatric program of Community Hospice of Northeast Florida providing hospice and palliative care services to children across a five county area in Northeast Florida. The ability of families to transfer between hospice care and palliative care offers options to families depending on medical status changes. Here are the experiences of one mother on the ability to transfer between programs.

Mackenzie's Story

My daughter Mackenzie Rose Tessaro was born on 10/21/2003. This seemed a normal pregnancy until 7:33 p.m. on the evening of her birth when we were told something was wrong but they did not know what. We thought she would just be like her five other siblings but eight days later we were told she had trisomy 18, "full blown"; is not such a great feeling! That was the moment we began a new education. Her daddy Jessie's reaction was "Ok fix it" and that's when they looked at us like we had two heads. Then the doctor explained this could not be fixed, that they were going to unhook the machines and we should go home and wait for her to die; the discussion was brutal. At that point hospice was called.

Our journey began: the hospice nurse came to the house, started to hold and love on her, and all at once we were a little less scared, not much, but a little. Then we find out she was missing a good part of her heart so the surgery began. Our nurse and social worker are there each day for four months and later we get a break and are home and stable for a while, then we went back and forth between home and the hospital for the next four years. When Mackenzie was five years old she was considered stable and we were told we would have to leave hospice. To say I was not happy about leaving my hospice care team is the understatement of the year, and I made this very clear to my social worker. I was told that we could transfer into another level of care within the program called "palliative." To my surprise nothing much changed. Mackenzie's care team made a few less visits but they have always been a phone call away. I will always consider Community Hospice part of our family. Mackenzie is still in palliative care and her team from community hospice and her family continue to love and care for our very stubborn little girl. We have plans for her 20th birthday party already.





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Here are the dates Mackenzie was in hospice and palliative care:

Pediatric Palliative Care 06/13/2008-current
Hospice 3/02/2004-6/06/2007
Pediatric Palliative Care 11/07/2003-03/02/2004
Hospice 10/29/2003-11/07/2003

Tara's Interview

Questions presented to Mrs. Tessaro regarding the ability to transfer between hospice and palliative care:

What was the most helpful in being able to go from palliative care to hospice care? Ease of transition, no change of nurse or social worker so you're still comfortable with those you have built a team with.

What was the most challenging in transferring between programs? Nothing

In your view what were the differences between the two levels/types of care?

The only difference I have found between the two programs is the frequency of check-in visits; other than that, everything is the same.

What would you recommend to families who are faced with changing from one level of care another? Change is scary with families that have an ill child. We have no control to make them better so we like things to stay the same because we have accepted (in most cases) where we are. For my family we were helped through the changes so they were not so rough. Slow and steady not reading the future into the change.

What would you recommend to the providers who provide the services? Communicate everything; listen to the family. Every family is different. Take one step at a time, not too fast.

Was there anything in the process (education to you from our staff, paperwork, services-equipment, meds, etc., billing of insurance/payments/financial) of transferring from one level to the other? Yes, they helped with transfers of medical equipment back and forth depending on which Level I was going to. Making phone calls until all was good and waiting for everything to be put into place before we actually made a change.

What impact (if any) did this have on siblings or other family members? No impact on family, We have seen same staff regardless of Level, which I believe is key.

Looking forward, what gives you the most comfort in knowing you are able to transfer from one level of care to another? I know whichever Level I am on I have a team with me. If I have medical questions, I call; if I am having a bad day, someone is there to talk.

What would be your biggest concern if you did not have the option of the palliative level of care? Losing my team of people, they are what make the program so great. They know Mackenzie, so they can speak honestly and call me back when I go a little overboard.



FREQUENTLY ASKED QUESTIONS: WHAT ARE THE DIFFERENCES BETWEEN PEDIATRIC HOSPICE AND PALLIATIVE CARE?

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In the looking at the differences in pediatric hospice and palliative care perhaps it is best to start with the similarities. According to NHPCO's *Facts and Figures: Pediatric Palliative and Hospice Care in America* (Friebert, 2009), pediatric palliative and/or hospice care is both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex, and /or life-threatening conditions and their families.

- Both focus on enhancing quality of life, minimizing suffering, and optimizing function.
- Both are delivered by an interdisciplinary team.
- Both can be provided concurrently with aggressive treatment.
- Both seek to achieve effective pain and symptom management.
- Differences can be broken down into these categories: timing of care, place care is delivered, payment for care, and availability of services.

Timing: When is it appropriate for a child or adolescent to receive palliative care and hospice services?

A patient is defined as eligible for hospice care by Medicare when they are given a prognosis of 6 months or less. Children are not typically covered by Medicare, but by Medicaid or private insurance. Medicaid and private insurance companies also abide by the six month or less prognosis rule. Thus, a child or adolescent may only be admitted into a hospice program when they meet the 6 month or less prognosis. Medical providers struggle greatly with "the 6 month or less prognosis." Children with life-threatening illnesses and chronic complex conditions are resilient and may often live longer than expected. Thus, this rule can often screen children out of hospice care.

Palliative care can be delivered to any child with a life-threatening illness throughout their disease trajectory. A patient could be followed by a palliative care service for years.

Another option that is now available for children with a life-threatening illness is "Concurrent Care" which allows children to receive both curative and hospice services simultaneously. Concurrent care for children is mandated by the Patient Protection and Affordable Care Act signed into law in 2010. To learn more about "Pediatric Concurrent Care," see the Briefing and other resources at www.nhpc.org/pediatrics.

Place: Where is the care delivered?

The majority of hospice care is delivered at home. However, hospice care can also be delivered in an inpatient setting, whether it be a hospice bed in a large institution or a free-standing hospice facility.

Palliative care can be delivered by a hospital team in the inpatient setting. Hospital palliative care programs may be consultative services, primary medical management programs, or designated palliative care beds or units. Pediatric palliative care may be provided in an out-patient clinic. There are also some palliative care programs throughout the country that make home visits.

Payment: What type of reimbursement is available for palliative care and hospice services?



Hospice care is paid for by Medicare, Medicaid, and most private insurances. There is a hospice benefit which covers the services of the interdisciplinary team providing care and includes standard equipment, medications, and supplies related to the terminal illness.

Palliative care is generally billed by the physician or other medical provider seeing the patient. Medications and other needed items related to the illness would all be billed separately. Again, Medicaid and private insurance would be billed. Often there is not a reimbursement structure in place to bill for needed services such as counseling or case management. Some hospices may also operate home health programs and provide palliative care services under that umbrella. Other programs may provide some services for free and utilize grants or philanthropy to subsidize services. Finally, some states do have Medicaid waivers where more inclusive palliative care services are provided. States with palliative care waivers include California, Colorado, Florida, and New York. *[See the editor's note that follows for more to come on this subject in issue #33 of this e-newsletter.]*

Availability of services: Are pediatric hospice and palliative care available throughout the country?

Hospice care is available throughout the country. According to NHPCO's *Pediatric Palliative and Hospice Care in America* report, 78% of hospices provide pediatric care and 36.6% have a pediatric program in place.

Pediatric palliative care is less available. Most large children's hospitals have pediatric palliative care programs. In the same NHPCO publication, a survey of Children's Oncology Group Institutions reported that 58% of institutions have a palliative care team, while 30.2 % of hospice programs reported providing a palliative care service (Friebert, 2009).

What are the differences between pediatric hospice and palliative care services and adult hospice and palliative care services?

Because of Concurrent Care, mandated by the Patient Protection and Affordable Care Act, children are able to pursue aggressive treatment and hospice care concurrently. *[Editors' note: the subject of concurrent care will be addressed in the next issue, #33, of this newsletter, which will follow in three months.]*

As touched on previously, children are more difficult to prognosticate than adults. They also take advantage of more aggressive treatment, are very resilient and thus live longer, and do not always fit into the traditional hospice criteria. It would not be uncommon to admit a child or adolescent who is very sick and declining into a hospice program only to see them do better than expected and need to be discharged from the hospice program and transitioned into a palliative service if available.

The age range is not just birth to 18, some mothers may receive a diagnosis perinatally and care can begin at that point. It may also be best to serve some young adults (18 – mid 20s) in a pediatric program as they are still being seen by pediatric specialists or they are best served by a pediatric team due to developmental concerns.

Ethical concerns are also different. The patient is a child and not the legal decision maker. Sometimes the patients are unable to speak for themselves due to age or developmental concerns. Pediatric programs need to be very mindful of any ethical issues.



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Friebert, S. (2009). *NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America*. Alexandria, VA: National Hospice and Palliative Care Organization.

Pediatric Concurrent Care. National Hospice and Palliative Care Organization. www.nhpco.org/pediatrics.



PEDIATRIC PALLIATIVE VS. HOSPICE CARE DEFINED: ARE THEY THE SAME? DIFFERENT? DOES IT MATTER?

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*"Ask yourself if what you're doing today is getting you closer to where you want to be tomorrow."
-Unknown*

The topic of this newsletter arose as some key people actively working in the field expressed concerns that as these newly-emerging disciplines of pediatric palliative and hospice care grow, even those of us who work in them, oftentimes don't really define how they're the same vs. how they're different. Some even ask, are they different, and relatedly, does it matter? Not surprisingly, in searching some of the literature and querying a few professionals in the field on what pediatric palliative vs. hospice care are, the responses to this search and the question are as varied as the sources and the healthcare professionals themselves. And if, as healthcare professionals providing this kind of care for our seriously- and chronically-ill pediatric patients potentially blur the lines between these two types of care, should we ever expect our patients and their families to come to an understanding of what a care plan that's comprised of one and/or both of these looks and "feels" like?

In looking to the literature, several definitions for pediatric palliative and/or hospice care emerge. Interestingly, and important to note, is that the definitions found are primarily for pediatric palliative care, without a distinction being made for hospice care. That is, either just pediatric palliative care was defined OR, the two types of care—pediatric palliative and pediatric hospice care-- were defined using the same terminology.

In the *National Hospice and Palliative Care Organization's NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America* Report, pediatric palliative and/or hospice care (PP/HC) are defined together as *"both a philosophy and an organized method for delivering competent, compassionate, and consistent care to children with chronic, complex and/or life-threatening conditions and their families."* The Report goes on to say that, *"This care focuses on enhancing quality of life, minimizing suffering, optimizing function, and providing opportunities for personal and spiritual growth. Planned and delivered through the collaborative efforts of an interdisciplinary team with the child, family and caregivers as its center, PP/HC can and should be provided along with concurrent disease-modifying therapy or as the main focus of care. PP/HC is achieved through a combination of active and compassionate therapies intended to comfort and support the child, as well as family members and other significant people in the child's life. Effective management of pain and other distressing symptoms, together with psychosocial and spiritual care, are of critical importance beginning at diagnosis and continuing throughout the entire course of a child's life and beyond."* The Report goes on to explain the differences between palliative and/or hospice care for adults vs. children, but does not specifically delineate between or provide separate definitions for pediatric palliative and pediatric hospice care. However, the Report does reference pediatric hospice as one of the models of care for seriously-ill children at the end-of-life as part of the continuum of care for these children in our communities, as do the NHPCO's *Standards of Practice for Pediatric Palliative Care and Hospice*.

According to the National Consensus Project for Quality Palliative Care, Third Edition, (2013), palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical,



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intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice. The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

The American Academy of Pediatrics in its Section on Hospice and Palliative Medicine states *“Pediatric palliative care is care designed to meet the unique and special needs of children living with life-threatening conditions such as cancer, muscular dystrophy, cystic fibrosis, severe brain problems, complications from prematurity and birth defects and rare disorders, among other conditions. Unlike many other forms of medical care, pediatric palliative care recognizes that everyone in the family is affected when one member is ill. Therefore, pediatric palliative care focuses on the needs of the patient and family: parents, brothers and sisters and other members of their support system. The focus of pediatric palliative care is to enhance the quality of life for all involved, in large part by preventing and alleviating, suffering using the skill and knowledge of a specialized care team, which includes doctors, nurses, social workers, chaplains, child life therapists, and others. Pediatric palliative care focuses on pain and symptom management, information sharing and advance care planning, practical, psychosocial and spiritual support, and coordination of care.”*

The World Health Organization's (WHO) definition of pediatric palliative care includes the following:

- *Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres, and even in children's homes.*

The Center to Advance Palliative Care (CAPC) says that pediatric palliative care is *“specialized medical care for children with serious illnesses. It focuses on providing relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the child and the family.”* The website goes on to say that *“Pediatric palliative care is provided by a team of doctors, nurses, and other specialists who work together with a child's other doctors as an extra layer of support. It is appropriate at any age and at any stage of an illness and can be provided along with treatment meant to cure.”* CAPC puts forth that *“Pediatric palliative care addresses a serious medical condition, including genetic disorders, cancer, prematurity neurologic disorders, heart and lung conditions and others. It relieves the symptoms of these diseases...in short, it helps the child and the family gain the strength to carry on with daily life.”* In its Glossary of Medical Terms, CAPC states that hospice (not specifically pediatric hospice) is *“Considered a mode of quality care, hospice focuses on relieving symptoms and supporting patients with a life expectancy of months, not years. Hospice involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support. The emphasis is on caring, not curing.”*



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Lastly, the American Academy of Hospice and Palliative Medicine (AAHPM) does not appear to, from my search of their website, have a specific definition for pediatric palliative and/or hospice care. However, they do make distinctions generally between palliative and hospice care as follows:

- *“Palliation is defined as ‘relieving or soothing the symptoms of a disease or disorder.’...Palliative care is for people of any age, and at any stage in an illness, whether that illness is curable, chronic or life-threatening...The overall goal of palliative care is to improve your and your family’s quality of life while you are ill...”*
- *“There is a specific type of palliative care—called hospice—for people for whom a cure is no longer possible and who likely have six months or less to live...Hospice care is about giving you control, dignity and comfort so you have the best possible quality of life during the time you have. Hospice care provides support and grief therapy for your loved ones.”*

In querying a few physicians who work in and/or practice pediatric palliative and hospice care, the responses ranged from how they think about these terms themselves to how they speak about them to their families, as evidenced by their e-mail responses to me:

“Palliative care has a goal of optimizing quality of life and re-defining, or re-focusing goals of care, as needed. It is not end-of-life care, although it is on the spectrum. Hospice care is end-of-life care, the major focus of which is the least worst death possible.”

“To palliate is to ease burdens, so palliative care is care focused on easing the burdens of patients and their families in all areas. Psychological, spiritual, practical, emotional, and medical burdens are all addressed by our team made up of people with many different specialists. The team members all work together to make it as easy as possible. We try to make an awful situation less awful, even if we can’t make it better.” This same physician then describes hospice care as *“Hospice is palliative care provided nearer to the end of someone’s life with the goal more towards comfort and quality than intervention and quantity of life, although some patients still have goals that include interventions to prolong life.”*

One doctor who heads up his Children’s Hospital’s Palliative Care Team said...*“I tell families this...“The palliative care team gets called when doctors, nurses, families or patients need help with the problems caused by a child’s serious condition. You already have doctors who are helping your child to GET better. Our job is to think about how to make him/her FEEL better. Our training and experience lets us often think of things no one has thought of before. Most of our patients are not at or close to the end of their life, but will for a long time need help. Try us, you’ll like us!”*

This same physician then goes on to write about how he describes palliative and hospice care to his patients and their families. *“Palliative care helps lots of kids with serious conditions and continues for years. Hospice care is a small, important part of palliative care... the special care that happens when care in the hospital is no longer the best course.”*

He then goes on to write...*“Hospice is a special kind of care that is for those patients whose families have decided that care in the hospital, and especially in the intensive care unit, is no longer helping them have the kind of life they want, even when life looks like now that it will not be long. If a child enters hospice care, a team with a nurse, a social worker, a chaplain, all backed up by a doctor, can help that child and the family get the most out of life. They are experts in controlling pain, vomiting, and tiredness. If you enter the home hospice program, they will do everything they can to help your child be a child (or a baby) and not be a patient like they are in the hospital. Hospice helps you be able to be at home with your child, and to ease the many burdens. A nurse can come to your house 24 hours a day, 7 days a week, if you need help. Some patients choose to bring their child to the hospice residence, where moms can be moms and there are nurses to do the nursing care.”*



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Another physician who heads a pediatric community-based hospice program writes...*"When I see patients and their family, I introduce myself as a palliative medicine physician. I state that I work with people who have serious or advanced conditions. I explain why the person qualifies for palliative medicine. I let them know that hospice is a type of palliative medicine for persons when their condition has advanced to the point where they will no longer get better. I let them know that they are (or are not) dying and that we (as a pediatric hospice team) work to try to have the person live as well as possible for as long as possible. I ask about what is important to them and what is left undone and try to focus our care on accomplishing those goals if possible. I identify that they do not have to hurt (or be nauseous or have too much difficulty breathing) and that it is really important to treat those things to ensure that they have as much life energy as possible (and to not waste it on their pain, dyspnea, etc.) to accomplish their goals. Our hospice team's responsibility is to walk with them along their journey no matter where it takes us all, and that they are not alone."*

After a readily-acknowledged not very comprehensive review of the literature, nor a broad-based survey of the pediatric palliative care physician population on this topic of what pediatric palliative vs. hospice care is, I now put my pediatric patient/family advocate hat on and offer some observations and commentary from a patient/family perspective. Please note that I'm not a medical person, but instead, a layperson who advocates for better supportive care for seriously-ill children and their families from diagnosis to death, so these observations are really offered up more from someone on the outside looking in with a patient/family lens to this issue. I raise some of these points more as "food for thought" for those healthcare professionals working in this field, with an eye towards how we can (and maybe should?) be communicating what these types of care are better to the patients and families in need of these pediatric palliative and hospice care services.

- There seem to be some indications that healthcare professionals are using the terms pediatric palliative care and hospice care interchangeably in talking about this field
- If they are an and/or type of care (e.g., pediatric palliative and/or hospice care), then why use two terms—why not simplify and narrow to one? If they're not different and are defined the same, then the use of two terms for the same type of care for our pediatric patients is likely, or can be, confusing to pediatric patients and their families
- If they are different (and there are some indications from this brief write-up that they are, but perhaps more from a timeline and/or payer/reimbursement perspective...end of life/last six months vs. prior to that), then there is still work to be done to be clear amongst ourselves, as well as with our patients and their families, about what each type of care is, what the benefits of each are, and when there is a transition to a more hospice-oriented care plan/benefits for pediatric patients as they move along the continuum of care
- Is the difference in these two types of care more of an insurance payer/reimbursement issue, than a patient/family care plan issue? That is, does the distinction between the two need to surface because hospice is a paid benefit whereas some PPC services are not? And importantly, does the Concurrent Care for Children Section 2302 provision call out the need for more definitive distinctions between the two, or not? What are the implications of all this for the conversations that need to be had with our pediatric patients and their families when the time comes? [Note: The next quarterly issue of this ChiPPS e-newsletter will help to provide an update on the status of the Concurrent Care for Children provision in the Affordable Care Act (ACA) and how some states/programs are trying to work towards offering palliative/hospice and curative care to their pediatric patients.]
- The last point I'd like to raise is the "Emperor has no clothes on" issue—that is, do we (or have we?) as an industry adopted the use of the term "pediatric palliative care" because we know that the "H-word" (i.e., "Hospice") scares our families and sends them running for the hills? Do we not like to broach the use of the word "hospice" because no family wants to know that they're at that



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point in their child's care—that there really is nothing more that can be done for him/her...that it's over? Does use of the term palliative care help to “soften” this blow and allow families to transition to hospice care under the guise of “palliative care” which may not sound as bad to them as hospice care?

In the end, pediatric palliative care is all about providing access to appropriate care that is family-centered around the seriously-ill child and his/her family. It's about making/keeping these kids comfortable, respecting and honoring the child and family's place as part of the care team, bolstering their strength and capacity to hope, and helping them to make the most of whatever quality time they may have together...whether 6 months or 6 years. Importantly, this care should start from the time of the child's diagnosis through the family's bereavement. In philosophy, it's about care for and support of the entire family along the child's continuum of care into grief and bereavement, if the child were to die. For the patients and their families, it may or may not matter what it's called (or if the palliative and/or hospice terms are even used), as long as the explanation of where they are in their child's illness trajectory is clear and their care plan options are made clear at every point along their child's illness continuum. That they are informed (and importantly, they understand in their language, in their context, in their culture) so they can best advocate on behalf of their child and that the child is comfortable are two of the primary end goals of care. The words and terms we use to get them there (e.g., palliative, hospice, comfort care, etc.) still seemingly require some work and perhaps some further discussion (and importantly, probably even with families of seriously-ill children) and standardization amongst those working in the field of pediatric palliative and hospice care.

If it's important that there are clear delineations between pediatric palliative and hospice care from a provider, and separately, from a patient/family perspective, this brief look might suggest we're not there yet. So, all of this takes me back to the quote at the start of this article whereby practitioners need to ask themselves, “Is what you're doing today getting all of us closer to where (and how) we want this field of pediatric palliative and hospice care to be thought of/defined tomorrow for those working in the field, as well as for the patients and families we serve in this field?”

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BILLING FOR PEDIATRIC HOSPICE/PALLIATIVE CARE

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Pediatric patients living with chronic life-limiting conditions often do not fall neatly into the usual "hospice" level of care with a continuous decline over six months ending in their early untimely death.

Children, on the whole, even when they are living with chronic medical conditions and become dependent upon medical technology will live for several years without evidence of decline and have more of a "roller-coaster" course of decline over their lifetime.

Therefore, due to the unique physiology of children, they are better suited for a palliative care program, bringing the full philosophy of quality of life and the interdisciplinary team members to meet their ongoing needs without having to move in and out of hospice due to no decline or death within the six-month limit.

The question often arises, about the potential for reimbursement for providing palliative care to pediatric patients and what strategies have been used for billing to at least cover some of the expenses incurred to provide for this care.

Hospice agencies are reimbursed through the model of a per diem for each patient enrolled as a hospice patient on each given day. This per diem reimbursement dollar value is "supposed" to cover the expenses related to caring for the patient including: providing durable medical equipment, medications related to the hospice diagnosis, as well as nursing, psychosocial, chaplain, and volunteer visits.

Physicians can be reimbursed separately through billing depending upon the arrangements between the physician and the hospice providing the care to the patient. I will not expand upon this except to note that there are resources available on the Center to Advance Palliative Care (www.capc.org) website.

Inpatient palliative care consult services are expanding rapidly within hospitals across the States including both adult and children's hospitals. There are many models for these consult services and have recently become more tightly structured with the advent of the Joint Commission Certification for Palliative Care in the hospital setting.

Palliative care clinics have started to become more available in larger medical centers, usually those with a comprehensive cancer and/or organ transplant program. Physicians and other interdisciplinary team members can assess and treat patients for symptom management through a referral process to the clinic. The revenue generated through physician billing is usually not adequate to meet the bottom line of running such a service, but it is agreed to be "the right thing to do."

Inpatient and outpatient palliative care consults can be billed when proper coding is utilized. A referring physician needs to consult the palliative care team for a specific question related to symptom management and/or goals of care. The note written by the palliative care physician needs to address the reason for the consult, identify the referring physician, and include a comprehensive note with recommendations. For palliative care consults billing is best done based on time spent with the patient and family. This is best reflected with a statement "more than 50% of total amount of face-to-face or floor/unit time was spent counseling/coordinating patient's care." Most notes are entered into an electronic medical record that gives an electronic date and time stamp. It is important to put total time



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spent and include time in and time out at the end of the note as well to help clarify the time spent with the patient/family as well as other professionals caring for the patient.

The V66.7 code is NOT a billable code. Billable codes must be symptoms related to the underlying medical condition. It is important to bill based on symptoms. Other physicians who are consulted to care for the patient are likely using the primary and secondary diagnoses and most insurance plans will not reimburse two physicians on the same date of service for treating the same diagnosis. This is why it is important to work closely with your billing people and to assist them by providing copies of your notes to help with proper coding and billing.

Palliative care visits done in the patient's home can likewise be billed. The above information is the same: referring physician, reason for referral, time spent in the home (not to include your travel time), and documentation with your recommendations and feedback to the referring physician. The codes are different reflecting the place of service is in the home.

As of the writing of this article, information regarding billing codes is as follows. There are only three levels for coding an inpatient initial consultation: 99221 (30 minutes); 99222 (50 minutes); and 99223 (70 minutes). Subsequent visits to the patient are likewise three levels: 99231 (15 minutes); 99232 (25 minutes); and 99233 (35 minutes). With the highest level of codes 99223 and 99233, you can also include "prolonged services" codes 99356 (1st hour) and 99357 (each additional 30 minutes) if you spent longer than the highest code allows you to code.

Outpatient codes are similar with initial visits being consultative and then all fall into subsequent visits.

The codes for home visit include new and established patient visit and have four levels ranging from 99341 to 99344 for new and 99347 to 99350. These codes also range in time spent increasing by 10 minutes for each code from 20 minutes to a maximum of 50 minutes. Again, you can add the prolonged services code to the maximum visit code for a home visit when appropriate.

It is extremely important that you work with your institution's billing department and introduce to them the palliative care program and have them assist you in "working denials." Oftentimes, it is necessary to include a copy of your note to ensure that they can assist in identifying the components necessary for a higher level of billing. Sometimes, all it takes is a sentence or two to bump the reimbursement up to the next level. Also, it is important to have the ability to "write-off" a non-reimbursed visit for a family, especially in the home setting. It has been my experience that insurance companies will reimburse the in-home visit after possibly first denying the claim. Again, the importance of working closely with your billing folks is evident.

A great resource for information related to billing for services can be found on the Center to Advance Palliative Care (www.capc.org) website. If you have not already registered as a member, I would highly suggest that you or a member of your team does so. The dialogue and repository of old posts includes a lot of wonderful information regarding not only billing but all aspects of running a palliative care program.



DEVELOPING A PEDIATRIC PALLIATIVE CARE PROGRAM IN WESTCHESTER COUNTY, NEW YORK

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Hospice & Palliative Care of Westchester (HPCW) is a not-for-profit, free-standing organization that provides care to adults and children in Westchester County.

Our mission is to provide extraordinary and dignified comfort, care and compassion to individuals and families facing a serious life-limiting illness. A child is a precious gift and when a child is diagnosed with a progressive, life-limiting illness, the entire family faces many challenges. Our Pediatric Palliative Care Team which includes seventeen members from all specialties is there to help during this most difficult of times.

The Pediatric Palliative Care initiative began to develop in 2011 after many years of caring for children. In September of that year, several team members attended a pediatric training at Morgan Stanley Hospital sponsored by Hospice & Palliative Care Association of New York State. Through this training, it became clear that there was more that could be done to better meet the needs of the community.

Internally, to enhance the program development, two separate teams were established: a clinical team where children on program would be discussed and a business team that would do community outreach to develop a program to partner with providers, develop fundraising initiatives, understand insurance reimbursements, collaborate with other community agencies and name the program.

In an effort to identify the specific needs of children, providers of acute pediatric care were invited to an open forum to discuss the needs of children in our community. All of these participants serve as referrers to us. From this meeting we learned that these pediatric providers were eager to have a palliative care program partner with them. They defined a need for children who return to their homes at the end stage of their illness and a wish to be able to offer an alternative to the acute care setting.

The transition of children from the acute care setting to a palliative care program, and often back and forth between the two, is a complex one. Not only do parents have to accept the finality of the disease process, they also struggle with balancing that with continuing curative treatment for their child. We believe that smooth transitions are critical and involve many resources to assure that they are accomplished in the most supportive way. These resources are not reimbursed.

The medical needs of the pediatric population are typically more complex requiring treatment methodologies that are often not used by adults. These modalities are often expensive and are not reimbursed at their full cost.

Due to the costs incurred by the delivery of care to this special population the Board of Directors developed a plan for fundraising. The development initiatives include the formation of a separate pediatric fundraising committee; the hiring of a grant writer; and outreach to the community and foundations. The initiative has been very successful.



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The business team has also submitted grant proposals to several foundations. To date we have received \$50,000 in grants.

The clinical team identified the need to have a pediatrician trained in hospice and palliative care available to them for collaboration regarding symptom management, case conferences, and education. A contract with Children's & Women's Physicians of Westchester, who service Maria Fareri Children's Hospital, has been signed and the services of a pediatric board-certified pain and palliative care MD has been secured. We believe this will further strengthen our program for care delivery as well as outreach.

Early in our discussions with the pediatric providers we learned that the word ***hospice*** could not be used. Many providers felt the ***hospice*** word meant imminent death to families who need to remain hopeful. This concept was re-enforced when we received a referral for a one-year-old boy with a brain tumor. A discharge planner who was not in attendance at our provider's meeting was very clear that the family ***could not*** hear the word ***hospice***. It was such a sensitive topic that many of our admission forms were changed to exclude the word ***hospice***.

As a result of this feedback choosing a name for the program became significant. An internal team representing clinicians, administrators, and a board member began the process for name selection. After nine months of intense work the name ***Comfort Crew*** was selected. The name has received positive feedback from many external to our organization. We now begin the development of logo and graphic design.

As we continue to move forward three themes remain constant:

- Provision of comprehensive palliative care to pediatric patients and their families
- Navigating the insurance world to assure full reimbursement. As of September, 2012, HPCW became a NYS palliative care provider under the Care At Home (CAH) I/II waiver program.
- Fundraising as an integral alternative of support to the program. There is ongoing research to identify additional potential donors.

Presently our focus is directed towards increasing awareness of the program among the providers and community resources. Team members will be visiting with and presenting our program to the pediatric teams (MD, SW, discharge planners) at area facilities that have been known to care for Westchester residents. Our goal is to serve 10 children this year.

At the onset of this program development, a year ago, we did not understand the complexities involved in establishing such a comprehensive program. As we meet with our providers to share our program development progression questions are posed which may identify aspects we have not yet considered! However, the foundation on which we are building, we believe, is very solid and will support growth and needed changes.



HOW DO PALLIATIVE CARE PHYSICIANS FEEL ABOUT PROVIDING CARE FOR PEDIATRIC PATIENTS?

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The early integration of palliative care has been endorsed for any child living with a potentially life-limiting illness, regardless of where that child may be on his or her illness trajectory.^{1,2} Although most children do not fall into this group, those who do represent a sizeable and growing population thanks in part to recent medical advances.³ Goals of care for children referred to specialist pediatric palliative care services often include maintaining a "normal" life, staying at home and being with family as much as possible, and avoiding hospitalizations.⁴ If these goals are to be realized, families of children with life-limiting illnesses will need to acquire supports in their local community. However, as children transition to end-of-life care, finding appropriate physician supports can sometimes prove challenging.

For families facing the death of a child, the best transition is no transition at all. Ideally, end-of-life care would be provided by the physician that knows the child and family best – often their primary care provider. Yet pediatricians may be reluctant to provide this care because of their perceived lack of training^{5,6} and inexperience⁷ with dying children, as well as the time commitment that may be required.⁸ Palliative care physicians who primarily look after dying adults represent another potential source of support in these situations. Unlike pediatricians, community palliative care physicians have a great deal of confidence caring for the dying and their practices are often designed to allow for home visits and addressing urgent crises. Moreover, physicians providing palliative care are generally accessible within most communities resulting from the ubiquitous need to care for dying adults.

But are palliative care physicians ready, willing and able to care for children? To investigate this, my colleagues and I undertook a study in which we electronically surveyed all physicians in the Division of Palliative Care at the University of Toronto, in Ontario, Canada.⁹ This single academic affiliation represents a heterogeneous group of physicians – solo and group practices; urban and rural settings; academic and community-based hospital affiliations; home, clinic and inpatient services. Forty-four of the 74 (59%) physicians responded. Slightly more than half (22/44, 52%) received formal pediatric lectures during their training. Less than 1/3 (12/43, 28%) had opportunities while training to care for children and only two of these experiences were during mandatory pediatric rotations. Not surprisingly, nearly 80% of respondents felt that their current training was insufficient to care for dying children.

One might think that their perceived lack of pediatric training and their discomfort with the various clinical domains presented in the survey would result in palliative care physician refusal or at least reluctance to care for dying children. Yet more than 70% (26/37) of our respondents indicated a willingness to provide end-of-life care to pediatric patients. Why? In short, respondents believed that they were the best suited physicians for the job. They appreciated that while differences between adult and pediatric patients certainly exist, the overall approach and principles of palliative care, as well as the potential benefits to patients and families, largely remain the same regardless of age.

Although it was reassuring that more than 2/3 of respondents would help care for children at the end of life, we wondered how, if at all, the proportion might be increased? Nearly all of the physicians in our



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study indicated that they would welcome the opportunity to receive additional pediatric training, but 1/3 felt that it was not essential. Perhaps there was an appreciation that without opportunity to put their knowledge into practice additional pediatric training would not necessarily lead to more comfort providing care to children. On average, physicians in our study reported caring for less than 1 child per year over the course of their total years in practice. Rather, what these palliative care physicians consistently desired most was having access to 24/7 pediatric expert mentorship and support. Willingness to care for children increased to 84% with the support of a general pediatrician, and to 95% with that of a pediatric palliative care specialist.

In Canada, there are 13 palliative medicine residency programs, only 2 of which have mandatory pediatric rotations. Palliative care is not yet a recognized subspecialty in Canada and so no formal pediatric learning objectives are required on a national scale. In contrast, the core competencies listed by the American Academy of Hospice and Palliative Medicine (AAHPM) state that “[b]asic pediatric palliative care competencies are essential for all palliative care specialists because, in many settings, no pediatric palliative care specialists are available, and adult specialists will be required to provide palliative care for dying children”.¹⁰ Nonetheless, an online search of the palliative medicine fellowship rotations offered in various US training programs suggests that the pediatric experience is both inconsistent and brief in most centers. Furthermore, formal pediatric learning objectives and experiences may instill a higher level of competency, but without sustained pediatric patient volumes after training palliative care physicians may not feel comfortable managing these patients.

In Toronto, we have begun identifying ways to improve palliative care physician engagement in the care of children. First, we recognized that in order to increase the sense of responsibility palliative physicians felt towards pediatric patients, the duty to care for dying children had to be embedded in their training, in accordance with the AAHPM competency statement. Although pediatric clinical rotations could not be mandated in the already tight 1-year training program, the palliative residency committee agreed that pediatric education should be included in the teaching each year. An interactive pediatric palliative care curriculum was developed that brings Toronto's palliative care and pediatric residents together, where they learn with expert facilitators and from each other. The primary objective of the curriculum is modest: to create an environment conducive to shared-learning, emphasizing the strengths of both groups of residents, in an effort to foster career-long partnerships for providing shared-care. Although the curriculum seeks to build pediatric palliative care competency, there is open acknowledgement of the infrequent opportunities these physicians may have to care for dying children during their careers. In light of this, the underlying message conveyed to participants is that their involvement in end-of-life care for children would always be accompanied by guidance and around-the-clock support of our pediatric palliative care team.

Time will tell if our efforts to improve palliative care physician attitudes and level of comfort towards pediatric patients are successful. What is apparent is that it is worth engaging this skilled group of individuals to help provide care for our pediatric patients in their local communities. Doing so will require more than just additional training and education. Models of shared-care and 24/7 support are required for our partners to feel confident doing the work, and ultimately for our patients and families to receive the best care possible at home.



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"OH MY GOODNESS, THEY WANT US TO TAKE A CHILD!"

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This article is from a series of presentations given by the same title by the author(s). The presentation was originally given at the NHPCO Management and Leadership Conference in Washington, DC, a few years ago. This is a topic that has consistently been requested by many, has been a source of trepidation, is a goal to strive for, and most definitely a need identified by many providers in the hospice and palliative care field. For the purpose of this article "pediatric patients" refers to individuals from prenatal to young adult.

What do you do when you get a referral for a pediatric patient? Throw up your hands and scream? Express an emphatic "No, we can't do that!?" Turn pale and fret because the need is there but you feel your staff is unprepared or will be in an uproar? Try to make it work despite the challenges? Any and all of these are not uncommon responses for a typical hospice and palliative care organization when asked to care for a child. For the majority of adult organizations there may only be 1-3 children/year that might require your care. How can you safely, ethically, and competently serve any of those children under these circumstances?

"Children are not just small adults" is an admonition heard often in the pediatric world, especially when discussing the prospect of care being provided to a child by adult practitioners. However, there is a growing need to provide hospice or palliative care services for children and an insufficient number of trained pediatric hospice and palliative care providers available in their communities. There are also a number of unique challenges facing organizations desiring to provide pediatric services. Pediatric patients are relatively rare, as mentioned above. The conditions leading to the need for hospice/palliative care are often different than those encountered in adults, and in fact they may be diagnoses you and your staff have never encountered. There is also a greater "ripple effect" when caring for children and timelines are often quite different for pediatric patients. In addition, growth and development factors such as physical size, emotional development, and cognitive ability, add to the complexity of caring for a pediatric patient. Finally, there may well be a degree of ambivalence toward palliative and hospice care by the patient, caregivers, and providers not typically encountered in adult practice.

Medically fragile children, children living with life-threatening or life-limiting conditions, are a significant and growing population in the US and the world. Children are living longer with conditions many have never heard of thanks to advances in medical care and technology. However, the pediatric population remains a small percentage of the total number of patients that would benefit from palliative or hospice care. Therefore, most hospice agencies are unable to hire staff members that are experts in pediatric care. The value of ad hoc experience from pediatricians, pediatric subspecialists, pediatric pharmacists, child life specialists, nurse practitioners, clinical nurse specialists, and others is quite apparent. However, having that experience available full time to provide care for 1-3 children/year is not financially feasible.



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Creating a network of available pediatric resources to help care for children is an effective way to provide these much needed services to such children and their families, as well as providing the support agency staff with the knowledge and support needed to provide the services. To create a network the following steps are suggested:

- Identify the expertise needed to support the level and nature of care required
- Recruit the expertise needed to competently provide the required care
- Provide training to the recruited experts regarding the scope of services that can be provided by the hospice and palliative care experts on your staff
- Train existing staff to provide the necessary scope of care, using the expertise of recruited experts
- Utilize needed expertise
- Recognize that this is a team effort

The spectrum of conditions encountered in pediatric palliative and hospice care is much broader than what is seen in an adult population. They include congenital abnormalities, perinatal accidents, progressive neurodegenerative and metabolic diseases, post-infectious encephalopathies, cancers, accidental and non-accidental trauma, to name just a few categories! How can staff cope?

The focus is on the child and family, not the condition. Recognition of the similarities rather than the differences and utilization of the network identified to provide support and expertise can overcome many of the challenges and fears that form a barrier to services for children and their families. Many if not all children who are referred and who may benefit from palliative or hospice care come with a network of providers. Most of these children will have several specialists as well as a primary healthcare provider. By openly discussing the needs and goals of the child and family, identifying the areas agency staff may need assistance, focusing on the expertise of the individuals involved, and working together, many more children and their families can benefit from the services that are the hallmark of hospice.

This does not mean that caring for children is easy. As mentioned earlier the "ripple effect" of caring for a dying child is usually far greater than in cases involving an adult. A dying child rarely dies alone; there are family, friends, classmates, sports teams, religious communities, and neighborhood communities. The volume and intensity of grief can overwhelm hospice providers, both experienced and inexperienced. Grief and bereavement counseling are a central part of adult hospice and palliative care—take advantage of that strength. Guide your organization's perspective—the more grief surrounding a death, the greater the opportunity to help. Helping your staff feel confident in dealing with the situation can be challenging but can also be incredibly rewarding.

Timelines are also different with pediatric patients. The timeline in terminal illness is typically dictated by the nature of the illness. The timeline for the conditions leading to the need for adult hospice and palliative care is generally fairly short and fairly predictable. The timeline for the conditions leading to the need for pediatric hospice and palliative care tends to be much longer and much less predictable. Additionally, adult care is characterized by "similarities" such as similar size, similar cognitive ability, similar emotional and psychological functioning. The variability between patients fluctuates within a range that an experienced adult hospice provider can manage. Pediatric care is characterized by differences: different ages, different sizes, different developmental stages, different emotional and psychological functioning. Pediatric care is also characterized by change. Strategies that worked last month, last week, or yesterday may no longer work today.

As the new Director for Patient Care Services for an adult hospice agency I was contacted to help find an agency that would care for a dying infant at home. Even in one of the counties with the largest population in the state of California, there were no agencies that would take a child. This mom's only wish was to be



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at home with her baby for whatever time they had left. There was no way I could refuse this family. Following the steps we outlined above, I contacted the primary care physician who would be overseeing the baby's care at home if not referred to hospice. We discussed the goals for care mom wanted, the services that were the hallmark of hospice, and the challenges with a staff that had only cared for adult patients. He agreed to be available to answer questions, to help with medication dosing if needed, and to continue as the primary care physician in partnership with the medical director of the hospice agency. The medical director, secure in the knowledge that the pediatrician would remain involved and available, agreed to accept the infant. The hospital pediatric palliative care team was also a part of our network and available to answer questions if needed.

Our staff was polled and volunteers were recruited to provide the services. In services were held to review the infant's condition, refresh staff members on infant assessment protocols, identify growth and development needs and the family's goals, and delineate services to be provided. None of the staff who volunteered had taken care of children in hospice, but had taken care of children while in school, in previous jobs, or had their own children at home. The most common initial response heard was, "I can never take care of a child." The social worker of the agency threatened to quit if we took the infant, announcing that there was no way she would be involved in the care. After discussing the situation, she agreed to participate, but only if she did not have to go to the home alone or touch the baby. Joint visits with the primary hospice nurse were scheduled. It took one visit with baby and mom for her to change her mind and she became one of the strongest advocates for building a pediatric program. Since then they have cared for several children of various ages and with various conditions. Each different and challenging, but as our social worker put it, "Once you get past the horror of a child dying, they are a family in need and who better than us to help them face the ultimate challenge. It is what we do best."

It is important to remember that a dying child is first a child. Most people in healthcare have some experience with children—trust your instincts. Specific expertise may not be part of your staff mix, but that does not mean you cannot provide expert pediatric care. The fact that the patients are different does not mean that your staff's skill sets are of no value. The challenge is getting your staff to realize this. Plan for the pediatric patient—there are approximately 2 million children living with a life-threatening condition in the US alone and this population is growing. Consider investing in a pediatric resource/trainer within your organization, but use the network to maintain competencies and expert guidance. NHPCO and ChiPPS have many resources for pediatric palliative and hospice care; most are free and downloadable from www.nhpc.org/pediatrics. Recently an online educational series for pediatric palliative and hospice care was created and is available for a nominal fee.

"A journey of a thousand miles begins with a single step." These wise words of Lao-tzu summarize both the challenge facing an adult hospice organization asked to care for a child and the solution to that challenge. What at first glance appears insurmountable becomes possible with careful planning and the willingness to take that first step.



Items of Interest

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

1. Register for NHPCO's 14th Clinical Team Conference (CTC) and Pediatric Intensive!

[Register online](#) or [download the registration form](#) to join us at CTC in Kansas City, MO. Enhance your conference experience with the Preconference Two-Day Pediatric Palliative Care Training (For New and Developing Pediatric Palliative and Hospice Care Professionals), Tuesday & Wednesday, September 24-25, 9:00 am – 5:00 pm.

2. Pediatric Palliative Care Training Series Bundle Discount. The Pediatric Palliative Care Training Series is complete and ready for purchase. This series of ten pediatric palliative care modules is specifically designed for pediatric palliative care professionals. NHPCO members can purchase the ten modules at once for just \$70. All modules are available with immediate continuing education (CE/CME) credit at no additional cost! Learn more and take advantage of this [member's only discount](#).

3. Pediatric Continuum Briefing Available. NHPCO's Mary J. Labyak Institute is pleased to offer a pediatric-focused continuum briefing, [Pediatric Concurrent Care](#) (PDF), available free of charge online. The goal of the continuum briefing is to help providers work together to assure that each state's most medically fragile children have the quality care they deserve.

4. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, nhpco.org/pediatrics. *ChiPPS is a program of the National Hospice and Palliative Care Organization.* Please e-mail [Christy Torkildson](mailto:Christy.Torkildson) to have your pediatric palliative care educational offering listed.

5. Subjects and Contributors for Future Issues of this Newsletter. In the many past issues of this newsletter, we have addressed a wide range of subjects. For our next issue, we are thinking about addressing concurrent care in various regions of the United States. If you know of good topics and/or contributors (including yourself) for this and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at christytork@gmail.com; Maureen Horgan at horgan.maureen@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

In the meantime, you can visit archived issues of this newsletter at www.nhpco.org/pediatrics. Among them, you will find articles on bereavement, sibling bereavement, self-care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, the role of pediatric palliative and hospice care in creating systems to support children, families, and the community, children are not little adults (i.e., respecting differences in providing pediatric palliative/hospice care), honoring volunteer perspectives, perinatal palliative and hospice care, and perspectives of fathers and other males.



Children's Project on Palliative/Hospice Services

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6. Reader's Corner. Our occasional Reader's Corner column provides 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 palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at christytork@gmail.com.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to Pediatrics@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, the Solutions Center will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the [ChiPPS Web page](#) for further materials and resources of interest.

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