ChiPPS E-Journal

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

National Hospice and Palliative Care Organization
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www.NHPCO.org/pediatrics
Welcome to the 41st issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a PDF collection of articles that explore selected issues in establishing and providing pediatric palliative/hospice care in different settings or in different ways. These articles offer suggestions for and examples of engaging in the important work of providing pediatric palliative/hospice care. Because this is a very important subject, we have chosen to devote two issues to these discussions and this is the second of those issues. Even so, we appreciate that no two issues or collections of articles will do justice to these broad topics, but we hope that the articles in this issue and in the one that preceded it will spur discussion, implementation, or expansion of programs in this field as a cooperative enterprise with children, adolescents, their family members, the professionals, the volunteers, and the organizations involved in their care. We welcome communications from anyone who has more to offer on these subjects.

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 NHPCO’s E-Journal Workgroup, chaired by Christy Torkildson. Archived issues of this publication are available at 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. Please contact Christy at christytork@gmail.com.
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Issue #41:
Establishing and Providing Pediatric Palliative/Hospice Care in Different Settings or in Different Ways, Part Two
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

Julian’s Joust: Excerpts from his Parents’ Web-based Journal Profiling the High and Low Points on their Son’s Journey through Cancer
Ann Fitzsimons, Executive Director of here4U, Inc.
In this article, the author offers comments by his parents that record a young boy’s struggles with cancer, along with observations to clarify events for readers.

The Role of the Medical Home for Children and Youth with Special Health Care Needs
Jessica M. Schmitt, MHA, and Renee Turchi, MD, MPH, FAAP
The concept of a “medical home” is explored in this article for children and youth with special health care needs. The authors conclude that, “The medical home is the standard of care for [such children], and is a tenable and high quality standard all patients and families deserve.” Editor’s notes list some additional resources on the medical home in relation to pediatric palliative/hospice care.

Starting (or Jump Starting) a Pediatric Palliative Care Program: Some Tips and One Team’s Experience
Joan “Jody” Chrastek, RN, DNP, CHPN
Here is practical advice framed in ways that are applicable to starting a pediatric palliative care program in many different settings. One useful comment to keep in mind: “Do not ask people to donate to dying children; rather invite them to be part of a program that helps children live fully and joyfully, even as they face life-limiting conditions.”

Lessons Learned from Starting a Pediatric Hospice Service as Part of an Adult Hospice Program
Barbara S. Zimmaro, RN, MSN, CRNP, CHPN, HTCP, HTAP
Pediatric hospice services often begin as an outgrowth of an adult hospice program. Here are some lessons learned from one such service, along with a flow chart illustrating some decisions made along the way. Some useful tips include: “redirect the team to be present and allow flexibility as families navigate the two arenas; remember to develop a caring trust with the family and child so that when the inevitable happens they turn to hospice for their support; be mindful always of what the family is dealing with and be present with kindness and compassion; remind yourself as a healthcare provider that you have always helped in some small or big way despite the outcome and/or direction the family takes.”

Developing a Pediatric Palliative and Hospice Care Program in the Community
Terry Eason, MPH, RN, CHPN
This article shows how a pediatric palliative/hospice program can be established to offer services in the community. There are challenges and barriers that need to be surmounted in doing this, but the author concludes that “it has been established that quality of life is positively impacted for the children and families through the wrap-around support and services of a community pediatric palliative care program, but additional research is needed to apprise third party payers of the expected financial impact on the potential of minimizing recurring hospitalizations and decreasing length of hospital stays.”

Developing the Interdisciplinary Team in Pediatric Palliative Care
Kathleen Davis, PhD
Many people fail to understand the differences between multidisciplinary teams and inter-disciplinary teams. This article explains the central differences, shows what defines the latter, and identifies their key components. While there are challenges to interdisciplinary teams, their importance is shown in the fact that “it takes the entire IDT to provide the care that is needed when a child has a serious or complex pediatric diagnosis.”
Is Your Interdisciplinary Team Complete? Engage a Pharmacist to Optimize Drug Therapy p. 31
Melissa Hunt, Pharm.D.
If we agree on the value of interdisciplinary teams in pediatric palliative and hospice care, who should be represented on the team? Among the not-so-obvious answers that might spring to mind, this article and the two that follow offer interesting suggestions. Here the value of a trained pediatric clinical pharmacist is proposed.

The Role of Music Therapy in Pediatric Palliative and Hospice Care p. 35
Lauren Anderson, MME, MT-BC
In this article, an extended case study is offered to show the value of music therapy as a useful component of the interdisciplinary team in pediatric palliative and hospice care.

The Role of the Speech Language Pathologist in Pediatric Palliative Care p. 38
Colleen Gould, M.S., L/CCC-SLP, IBCLC
At first, it seemed strange to this author that a Speech Language Pathologist could have a constructive role to play in helping patients to live in pediatric palliative care. Here she uses practical examples to show how she learned that specialists in this discipline could, in fact, contribute in important ways to the work of interdisciplinary teams in this form of care.

Reader’s Corner p. 41
Suzanne S. Toce, MD
Our occasional series of Reader’s Corner articles seek to bring to the attention of readers articles and other publications that are relevant to pediatric palliative/hospice care. Here are descriptions of three journal articles, summarizing in each case the contents of the article, noting what is special about it, identifying to whom it is most relevant, and pointing out how its contents can be applied. The first article is on pediatric palliative care and the medical home; the second is on the co-management of medically complex children by subspecialists, generalists, and care coordinators; the third identifies questions to consider when caring for a child with a high risk of dying before adulthood.

Items of Interest p. 44
In each issue of our ChiPPS E-Journal, we offer additional items of interest.
This is a story of a Julian Ross, a young boy with cancer, and his family—Mom Kristi, Dad Steve, and his brothers, Alexander and Brayden. It’s an all-too-familiar story to those who work in pediatric oncology and pediatric palliative or hospice care. It’s a story of what it was like to be Julian, and his family, as they engaged in combat with an enemy they couldn’t really see. Yes, the literature is beginning to tell us not to call these cancer journeys “battles” or “fights,” as that implies there are “Winners” and “Losers,” but to Julian’s family, this is what their journey was—a full-out combat in which they would do anything and everything they could to cure Julian. And when that was no longer possible, to get him home with competent and compassionate comfort care so he could live out his final days in his own home, on his own terms. Unfortunately, that was not how Julian’s story was to end.

With the permission of Julian’s Mom, this article will share with the reader “real time” excerpts from a Facebook page that Julian’s Mom and Dad posted to throughout Julian’s journey with Stage IV neuroblastoma, called Julian’s Joust (www.https://www.facebook.com/JuliansJoust?fref=ts).

The purpose of sharing these posts is to help demonstrate what it’s like for these families to receive care for their child across a multitude of different care settings. In this case, at home, in a local community clinic and hospital near home, in a highly-specialized children’s hospital, in an out-of-town hospital during a vacation trip when Julian fell ill, and in a different home (not his own) for end-of-life care. This family, like many families of children with chronic or terminal illnesses, has seen and experienced it all across a variety of healthcare and non-healthcare settings, which these Facebook posts will illustrate. By sharing Julian’s journey, we hope that the healthcare professionals who care for children like Julian, and others with life-limiting and/or life-threatening illnesses, can begin to see how complicated this care is for the family, and start to think about ways to make this care a little easier, a little less stressful, and a lot more coordinated across their child’s care continuum.

3/15/13

This is dad with a brief update. Julian woke up about 45 minutes ago complaining that his knee area on his right leg hurt “very, very bad” to the point he started to cry. I’m hoping it’s the way he slept last night...he has a very high pain tolerance and for him to cry tells me it must really hurt.

I guess the anxiety has started to kick in with the upcoming scans on Monday and Tuesday as well as the bone marrow aspirations. Please keep him in your thoughts and prayers that he remains NED. If the scans or bone marrow show up with any cancer, he will be excluded from this Phase II study which remains his only available form of treatment at this time.

Julian has clinic this morning at our local children's hospital in NY. Sunday we head to another more specialized out-of-state children's hospital for his scans and tests.
8/4/13

Two years ago today marks the day we found out Julian had a massive tumor in his abdomen. The medical staff suspected Neuroblastoma but couldn't give us the final diagnosis of that form or its staging for a few days. We all can remember it like it was hours ago, not years ago...our world became dark and sad...we were told that he'd likely not survive it, that he had only months to live. We are thankful to God to have blessed us with so many miracles and the gift of having our son for longer.

10/3/13

Got Meds????

This does not include synthroid, Benadryl, Tylenol, advan, cefdoximine, and Imodium.

3/24/14

Chemo. Dasatinib likely side effects: Low white blood cells, and Red blood cells, low platelets, diarrhea, nausea, a feeling of extreme tiredness not relieved by sleep, muscle pain, headache, shortness of breath, fluid buildup between the layers of tissue between lungs and chest cavity, and skin rash.

Rapamycin: Nausea and vomiting, increased blood pressure, decreased kidney function, diarrhea, increased cholesterol and triglycerides. I am telling you the crap the kids go through for a cure is insane!

5/25/2014

Please keep Julian in your prayers. We are on our way to our local children’s hospital’s ER. Julian is having extreme headaches. He started a new cycle of chemotherapy today and 15mg of morphine, Tylenol, and Ativan hasn’t been able to touch it. He hasn’t been able to keep anything (liquids or solids) in him.

10/14/14

We had a very busy day today. Good news, look at those counts below. His platelets are 101; on their own his stem cells are taking off. The bad part: two of his liver function tests are high. His alanine amino transferase (ALT) is 192; it should be between 10 and 35. His Aspartate amino transferase (AST) is 135; it should be 15-40. He has an irritated liver. We will watch it and wait. Julian started his metronomic chemo on Sunday. He takes 2 Celebrex a day and 1 cyclophosphamide. He takes them like a champ! He
also got his flu shot on Monday. He went into the room without me, I waited with Bray outside. We could hear him instructing his nurse exactly where he prefers to get poked. They got into a debate about the length of the needle and he said he really wouldn't be happy if she got his bone. The brave little man didn't say a word, took it like the hero he is. Mommy got in a car accident on Saturday and the van is pretty much totaled. We have been frantically looking for an affordable replacement and thank the good lord, we did. That was picked up, registered, and on the road today.

1/14/15

Little man had his head CT and thankfully he has NO solid tumor in his brain. He does have it throughout the bone marrow of his skull. Tomorrow, we will hear if the research Institute will still accept Julian into the trial in light of the recent circumstances. If they say no, we have nothing. Chemo would make him critically ill. MIBG Therapy would kill his counts and they would not recover. There is too much cancer to radiate. Dr. M. will be doing a bilateral bone marrow aspiration tomorrow morning. Then, Dr. Mo will send it off to a molecular lab to be tested to see IF any drugs would fight it. Time, unfortunately is the enemy.

2/8/15

This is Julian's dad: it is a little after midnight and Julian remains asleep. A little while ago he woke and asked for some juice. He's at this point not in any pain. Mommy is sleeping next to him and I am in his wheelchair which is on the other side. At points he wakes to say things that don't make sense, so I'm not sure if he is hallucinating. Honestly I can't go to sleep as I fear if I close my eyes I may miss his transition. While I sit here, I beg and pray for a miracle. It was so hard to hear my son given last rights and I honestly lost it. Even harder was discussing funeral arrangements and the whole time I was hoping I would wake up from this bad dream. I feel so helpless, as mom does too. I do not wish it on any parent.

3/2/15

Good evening all. The little man had a rough day, however is very happy that Incare came and took the hospital bed. Daddy and I lugged our bed back downstairs, set it up, and added Julian’s air pressure pad. Now, he can snuggle.

3/7/15

I love goals! Julian has been feeling better each day! Eating is picking up. He informed us he is going to go to Great Wolf lodge in Canada and Disney as long as it isn't snowing! He gets stronger and I swear I WILL get him there!

3/22/15

They are seeing if we can move rooms to one with a window with a view outside. Then I will post the address where you can send mail. We want to put clings and such in the Windows to make this a happy room.

5/9/15

Good evening Army. Little man had an ok day. We were battling nausea today, but hopefully we are on the up side. Daddy went home today and filmed the video below this evening. This is a HUGE fire hazard and because of that Julian probably won't get to go home if they can arrange it. This electric sparking is right outside my front door just below our meter. We need to find an electrician ASAP. Can we get a little break PLEASE lord?

Author's Note: By this time, Julian had been in the hospital for close to 90 days and had decided that he wanted to go home. There were no new treatment options to try and Julian just wanted to go home to his own house, bed, pets, and friends...to his life before cancer. However, he and his family lived in upstate
New York, but he was being cared for at a Children’s Hospital in another state, so his family was facing barriers to bringing him home under hospice care. Seems the local hospice in upstate New York couldn’t handle/weren’t comfortable with managing Julian’s pain meds through his pump, so he was denied hospice care in his own home. As a result, the family and supporters took to the web to get Julian home under hospice care where his story went viral and achieved 27,000 FB Likes (it’s now at 34,999).

Cincinnati Bengals player, Devon Still, whose daughter Leah, is also battling neuroblastoma, was in the hospital the same time as Julian and befriended the family and their plight and took to Instagram in support, resulting in thousands of encouraging messages and local and national media attention to help garner support for Julian’s wish to go home to die.

6/12/15

This is dad with an update. As most of you know, Julian's story was shown on TV here and in Chicago. We’re all in shock of how far the story has spread and thank everyone who’s become involved with this issue. I owe a special thank you to a friend and a fellow cancer father, Devon Still, for helping Julian's plight be known. Devon is a great man, an amazing father, and a wonderful friend we’ve been blessed to have in our family’s lives. Cancer doesn't discriminate; it sees no difference in one's race, social economic status, or even fame. Therefore we see each and every one of us as part of a family, “the cancer family. “Some people believe that we have lost hope in a miracle. Absolutely not. While Julian lives and breathes, there’s always hope...Trying to get Julian out of the hospital is not giving up or giving in as some have said. It’s parents trying to fulfill the request of a sick child, to rekindle his will to live....Imagine not being able to leave a building, to go down the road, smell the flowers in bloom, see a movie, have your pet sleep with you, even just go to a store - now think back to when you were 10 years old...After being confined for close to 90 days, wouldn't you want to leave?

We appreciate all the medical personnel who are coming forward to try to help Julian get home. Especially the nurses that have come forward and offered to volunteer. Thank you. Please contact us via a private message with the type of nurse you are (RN or LPN) and how you could help. Getting volunteers is fantastic and we appreciate it. With that being said, I’m not sure if it will allow Julian to still leave the hospital and it's something that we’re going to check into today. Why do I say that? There are controlled substances involved in Julian's care and by law there has to be responsible parties to handle the drug and pump. I believe that is one of the reasons why an agency was needed, but I could be wrong. I'm not an attorney and do not know the law.

Even if Julian’s dream to leave is resolved or not, we cannot and will not give up on this issue. We need to change how current conditions are for pediatric hospice patients. Julian’s plight has shown us how his problem isn't limited to one area of the U.S. It's something that needs to be addressed and fixed. It needs to be corrected so that another child and family do not have to go through this.

Sorry for the long-winded speech...you all probably want to know how Julian is doing. Right now at almost 4:30 AM, he’s sleeping. Julian complained about eye pain, knee pain, and foot pain on and off for the whole day. The bumps on his skull still remain and no one can tell exactly what it is without scan. Luckily, he did not need blood or platelets, but his blood work is showing Julian is fighting something...maybe an infection - which we hope and pray it’s not since his back bedsore has exposed his sacrum. An infection could kill him in a short period of time. Other than that, Julian still has no fevers, clear lungs, a strong heart, normal input and output. His appetite is steady and he’s slowly putting back on the weight he lost.

Author’s Note: Julian was finally released from the children’s hospital to the home of two women who open their home to people needing a place to be cared for. The home was near the out-of-state children’s hospital Julian was being cared for at so they could continue to help assist hospice and manage his care. However he was not able to go to his own home under hospice care due to his local hospice not being able to and/or comfortable with managing his pain meds.

6/24/15
Good afternoon all!!!!! Sorry for the lack of update but you'll understand in a moment. Yesterday, we were discharged. Hospital security escorted Julian out through the wood center where he was greeted by LOTS of Wounded Warrior riders and several police cars. They escorted us all the way to our new home. To say it was incredible is a vast understatement!!!!! Thank you to the people who opened their home to us and arranged the escort, our wonderful hospice team, the Pediatric Palliative Care team, our nurses, and all of The WWR and police and fire departments!!!! After we got all settled in, the news broadcasted a Tornado watch. Within moments it hit!!!!! All of us huddled in the basement and waited it out and are just fine. The power is out and trees are down everywhere!!!! The next challenge was Julian's equipment. One of the amazing neighbors bought a generator and the fire department tirelessly fought to get it running!!!!! They were prepared to transfer Julian to the hospital, but thankfully we can stay put for now. We will update when we can!

Author's Note: While at this home under hospice care, Julian, and his family, experienced all that is good about palliative and hospice care as they were all cared for body, mind, and spirit. His physical needs were cared for and his pain was being managed, his psychosocial needs were met as he, and his family, had many, many visits from home and support from the local community. His spiritual needs were also addressed as he made his First Communion and Confirmation (all attended by a priest and 4 monks, the hospice chaplain, and even his Doctor, Nurse, and Social Worker). He also had home visits from the Doctor, Nurse, and Social Worker who cared for him for three years, as well as the Pediatric Palliative Care Team from this same children's hospital. Hospice helped Julian's family do some legacy activities during this time, including making a beautiful handprint art of all of them with Julian. While under hospice care, Julian seemed to rally and gain strength and as he got a little stronger, his family scheduled a Julian “bucket list” Disney trip. Unfortunately, Julian fell ill while on the trip and the following excerpt picks up from there.

7/31/15

This is dad with an update. Julian has a message for you. We thank you all for your love and prayers. This was recorded a few minutes ago and as the video shows it appears that Julian has possibly had a stroke. He's talking using only part of his mouth and now is unable to use his right arm. We've moved our Sunday flight up to tomorrow morning. So he can be seen at the out-of-state children's hospital again. Since he's on hospice there is very little that they can do for him. We're praying for a miracle and still are remaining positive even at this time. Please keep him in your thoughts and prayers.

8/1/15

We arrived safely thanks to the hard work of the local children's hospital and transport team in Florida, the transport for the plane that brought the out-of-state children's hospital transport team to FL, and to Dr. Mo for pushing everyone along! Julian has not had a seizure since this morning. They have been giving him Keppra to control it and he is doing better! We are in the same room we were in before during our last 100-day stay. Dad and Bray are on a plane which will arrive at 10:04 pm tonight. Thank you everyone so much for your prayers, love, and support. While at the children's hospital in Florida, they were amazing and took wonderful care of us! If you ever have the pleasure of meeting Dr. L, tell him thank you for his incredible compassion with Julian and the kids under his care! Also, we had a wonderful nurse and Angels for Talia momma came to keep us company.

8/8/15

After returning to the out-of-state children’s hospital and spending 7 days there, Julian Thomas Ross died in the hospital on August 8th, 2015, never getting to go home to his own house despite being gone from his home for nearly 6 months, with a lot of this time in the hospital. He had had many visitors during his final week of life, including family, friends, and even a therapy dog. He is lovingly remembered by his family and friends, his cadre of healthcare teams in New York, Philadelphia, and Florida, and his Army of 35,000 Facebook Followers. In an email to me as this story was being written, Julian's Mom wrote “In
most of the places where Julian was cared for, he was a child, and not a patient. They (his healthcare team) teased him, laughed with him, played with him, hugged him, kissed him, and cried with us when he left."

Author’s Note: As a postscript to Julian’s story, this was a more recent Facebook post (ironically two months after he died) that drives home some of the consequences of families choosing at-home hospice care for their kids, wherever they can get it. Not only is there a gap in at-home hospice services for children, but when they find a way to get them that’s out of their coverage area, there seemingly are huge insurance coverage issues associated with that, or at least there were, in this instance.

10/8/15

What is the price for a child battling cancer? Well look below. We were charged $1,265,334.25. We owe $844,942.29!!!!!!! All because our insurance company deemed him being in a hospital outside of our local area (and receiving hospice care near there but not near home as it wasn’t available) not medically necessary. So, we could NOT leave the hospital without hospice services, yet our own county hospice wouldn't take him. Explain that to me???
THE ROLE OF THE MEDICAL HOME FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)

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Pennsylvania Medical Home Initiative
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“Medical Home” has become a buzz word in the healthcare community over the past several years. Initially, many thought it was a physical location, maybe some type of nursing home. As more primary care providers are adopting this concept of care within their practices and politicians are mentioning it in their speeches, the fact that it is more of a philosophy of how to practice medicine has become more apparent. Most, however, do not know the “Medical Home” concept originated over 40 years ago in the world of pediatrics.

In 1967, the term was first used to describe the concept of the general pediatric practice as the central source or “home” of a child’s medical records. Conceptually, there would be one central location for information such as vaccinations, growth charts, past medical history, and other relevant information. However, it became apparent that a more in-depth medical home was needed for children and youth with special health care needs (CYSHCN). Often times CYSHCN have multiple care providers, specialists needed, various services, and community partners involved in their care making it difficult to keep track of all of the information. General pediatric practices help patients and their families obtain needed care, while coordinating the care to ensure no duplication or gaps ensued.

Practices that are medical homes take the driver’s seat in facilitating CYSHCN move forward in the winding road of the continuum of their care. A central medical home function is identifying their CYSHCN to track them, manage their care needs, and ensure continuity and quality. This is typically done with the creation of a patient registry. CYSHCN are identified by the medical provider and are added to the registry ensuring the practice can regularly monitor the status of these patients and any outstanding action items. With practices now having larger panels of patients, it would be difficult to effectively manage all of the CYSHCN without a tool like the registry. In the current world of electronic health records (EHRs), many practices have registry functions built in to their systems, which makes the process even more seamless.

Care plans are very important for CYSHCN and something that a medical home help develop with the patients and their families. These care plans provide the outline of the patient's medical care, summarize past medical and relevant services, providers, medications, and also provide valuable information regarding non-medical services such as education, therapies, and behavioral/mental health supports. These plans are designed to be shared with various providers of care, including specialists, home care, palliative care, therapists, medical equipment providers, school nurses, and teachers. This helps everyone involved in the care of the patient, including the family; understand who all the players are and their roles in the patient’s care continuum.

A key role in any medical home practice is that of the care coordinator. While some believe a care coordinator needs to be a social worker or registered nurse, many practices use licensed practical nurses, medical assistants, physician assistants, or nurse practitioners. This role may also not be the person's only responsibility at the practice. It all depends on the practice and their staffing model, workflow, and dynamics.

Care coordinators manage and maintain the patient registry, monitoring the practice’s CYSHCN on the list and their needed coordination of care. They ensure the patient is going to the recommended specialists, and may even help the family to schedule the visits and transportation. They help to ensure
that laboratory and imaging results are obtained/received or investigate reasons why they may not have been obtained. They also follow up on special education needs for patients and help complete forms needed to obtain appropriate and needed services at school or home. A care coordinator will work closely with home nursing and palliative care agencies to ensure needed forms and paperwork are completed properly, covering services and educating families on who to call for what issues as they arise. They also provide a strong link to community resources available to patients that families are not aware of. Additionally, care coordinators will guide families along the complex road of insurance companies, assisting them in getting service pre-authorized, medications covered, and durable medical equipment provided.

A pediatric medical home strives to provide as many resources and connections to patients and families as possible. Practices develop relationships with various local agencies, charities, education groups, and advocates to use as resources for themselves and their families. Many pediatric medical home practices also develop parent partners. These are parents/caregivers of CYSHCN within their own practice acting as mentors and resources for other families of CYSHCN. Since they have already been down the path of specialists visits, home care, special education, and so on; they are an invaluable resource for families.

Pediatric medical homes also work with families and patients when it is time to transition to an adult-based primary care provider. For many patients and their families, there is a strong connection and trust that has been built over the years with their medical home that makes it harder to move on to a new provider. But medically, it is no longer appropriate for a 22 or 23-year-old patient to see a pediatrician. Care coordinators at the pediatric medical home will help families find an adult-based primary care provider in their area to whom they can transition their care. Medical records can be transferred over prior to the first visit and care coordinators or medical providers can speak to the new primary care practice to review records and pass on any important information. The goal of the transition to an adult-based practice is to be as smooth and uninterrupted as possible for the patient and family.

Medical homes have taken steps to make sure that their children and youth with special health care needs have their medical care coordinated and tracked to help achieve optimal outcomes for the patient, family, and all care givers and providers of services involved. By taking these extra steps, medical homes have not only streamlined their workflows for CYSHCN but also that of the patients other providers. The medical home is the standard of care for CYSHCN, and is a tenable and high quality standard all patients and families deserve.

Reference:

Editor’s Note: Some additional resources on the medical home in relation to pediatric palliative/hospice care include:


STARTING (OR JUMP STARTING) A PEDIATRIC PALLIATIVE CARE PROGRAM:
SOME TIPS AND ONE TEAM’S EXPERIENCE

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Since the Institute of medicine report “When Children Die” in 2003, the growth in pediatric palliative care programs has been remarkable. Children’s hospitals and adult hospitals with pediatric units or “hospitals within a hospital” have been developing palliative care services for children and their families. These programs vary widely depending on a number of factors such as the type of institution, place of care, and corporate culture.

“When you have seen one pediatric palliative care program … You have seen ONE pediatric palliative care program!” – Different programs for different needs.

An adult hospice program may extend itself to care for children when the need arises. This is often seen in rural areas where specialized pediatric services are not available. Larger programs may have a sub set of clinicians who are the “peds team” and may or may not also care for adults. These programs tend to have a small but consistent number of pediatric cases. Institutions that have larger number of pediatric patients may have a designated team for pediatric palliative care, seen most commonly in children’s hospitals or large home-based institutions having a high daily pediatric census. There are also free-standing pediatric hospices and other creative new ideas sprouting up to provide care to meet unique needs. Whatever form a program takes it is of course essential to follow the precepts of pediatric palliative care. It must be an active and total approach to care provided by a team, embracing physical, emotional, social, and spiritual elements, providing care through death and bereavement. Continuity of care is a shared goal. How this is practically provided will vary according to the needs, resources, and program mission and vision.

One team’s experience: Many in the institutions, both hospital and home care, knew there was a need for providing more palliative care, informal meetings turned into regular formal meeting, parents were invited, and there was much enthusiasm. Those involved were not sure how it should look or what it should be named. They were struggling to get traction with the administration. Everyone thought it was a good idea, but “no money for it this year… and palliative care is end-of-life care right?” There was a barrier with the name.

Aligning your goals

Be realistic about what your institution wants. Consider how you can help support the institution’s goals and you will find palliative care will integrate nicely with them. For example, increasing patient satisfaction is a common goal for an institution. By providing expert symptom management, psychosocial support, and coordination of care, patient satisfaction will be improved.

This may be frustrating to some who feel the need to move quickly, yet this collaboration and alignment will provide a strong foundation for a program that will be supported, resilient, and an integral part of your institution.

The palliative care group started meeting with key stakeholders, not to tell them what they needed but asking “Who are the most difficult patients? What would help you?” For this group many physicians found family decision making hard as it is necessarily a time-consuming process. Others talked about how hard it was to find a community hospice that would take kids. An institutional goal was to better serve their patients and families.
The group brainstormed about how to be available to help be with families as they processed difficult decisions and provide those longer but needed visits. Another group collaborated with a community hospice and the state hospice organization to work together to meet the needs of children in outlying areas, thus improving services to families, both in the hospital and on discharge. The interactions with the community providers were undertaken with the same concepts and attitude of collaboration, with equal challenges and successes.

The word “palliative” was a barrier that kept children from getting the care they needed in the institution. The group took on the name pediatric advanced complex care team PACCT. “We provide an extra layer of support for children with complex chronic conditions, palliative care, and hospice.” Interestingly, that helped to open doors that were not open before.

Needs assessment

Before planning a program or growing to the next stage, it is essential to do needs assessment. This does not need to be a long and formal process, but it is important to look carefully at what is needed, both in the short and long term. Passion is an essential ingredient to starting a program, but for it to succeed long term it must be balanced with practicality and sound business practice.

Be realistic about what your institution needs. What sort of patient volume would you expect to need palliative care services? If the expected patient volume is not large, you may not require a stand-alone, fully staffed team. You may find that a “float palliative care team” with members from different specialties better fits what is needed and applicable in your setting. There are helpful online tools to assist you in estimating the patient volume and the required staffing to meet the needs. These can be found on the Center to Advance Palliative Care (CAPC) website (www.capc.org). Are there other programs within your institution or an affiliated institution that you could collaborate with? Perhaps there is an adult palliative care team, a bereavement program, or an NICU perinatal hospice team that has similar goals and missions. Assessing what is presently available but still needed avoids duplication of services and those dreaded “turf wars.”

What does your team need? You may have identified a team that is interested in providing palliative care. Take time to assess what skills are in the team and what further training is needed. Often we don’t know what we don’t know! Of utmost importance is attention to the team, its knowledge, attitude, and skills in palliative care, but also team dynamics. The latter is a topic that often goes unattended, and can result in the death of an excellent team.

In the discussions across the institution it was clear people wanted more palliative care education. This was also an institutional priority. PACCT sponsored an ELNEC training course, with volunteer presenters from the neonatal and intensive care units. This provided a great opportunity for collaboration, team work, and education. It developed more bedside advocates for palliative care and raised awareness throughout the institution.

Planning and visioning: Start small and dream big

“…Where there is no vision, the people perish”

As you plan to develop, or grow, your program take time to think about what your institution’s long term goals are and how the palliative care program can align with those goals. Dream big but remember it starts with small steps. Take time to develop the vision with the team; it needs to be a shared vision. Together you can work out what the practical steps are. Start small and dream big. After every meeting have an achievable plan for what is your next small step. “What can we do by next Tuesday?” Just one small step, a conversation, an email sent will be a step in the right direction.

A PACCT member talked to the head of Oncology when she was rounding about what the group was
doing. She happened to have lunch with the hospital and Home care CEOs and mentioned it; they were both interested and invited a representative from PACCT to come and talk with their leadership groups. People across the board were beginning to see the increased need as they all better understood that PACCT offered care across the spectrum of serious conditions and that palliative care is not “the death and dying squad” but a resource for many.

Resource assessment or reassessment

Everyone has resources. They may not be financial, but they may be even better—enthusiastic people! Take time as a group to discuss, brain storm, and list who are your allies in your institution and how to engage them. Talk about what they see as the needs for this population are. Speak not only with your natural allies but also those you least expect. Always include families; their voices are essential in the growing process. Approach the approachable... leave the “late adopters” till later.

Don’t forget those in the community outside the hospital.

The team had no funding, but as they talked to others, spread the word, and showed people what could be done, attitudes began to change. The team’s “what can I do to help?” approach opened opportunities. A board member who also was a parent of a child needing palliative care was approached by a team member to see if she would join the committee to improve palliative care. She has been an enthusiastic member since and has opened many doors.

Collaboration

Although collaboration takes time and sometimes seems to slow the process down, it is an essential part of growing a program. When the major stakeholders are included early in the planning, their support can be part of a strong sustainable foundation. Who are the people that interact with the child in your institution? Brain storming with your team may result in a larger number than expected. Talk with them, keep communications open, and bring people in early in the planning.

PACCT members asked if they could attend unit rounds. When they starting asking and offering ways to help and unit staff saw the help made a difference in their work and the lives of the families, PACCT was welcomed in with unexpected warmth to share the work. PACCT also reached out to the home care teams providing education and mentoring to decrease the anxiety of the home care staff who were initially hesitant to provide palliative care for children.

Barriers

Sometimes when we are full of passion for a project and see what good it can do, we can forget that there will be barriers. It is important to anticipate them as a team and discuss how to address them. Think about what barriers you have already come up against in your work to improve access to palliative care, try to understand the view point of your opposition and their concerns. It is only by coming alongside others and understanding their fears and concerns that many barriers can be dissolved. Some of the barriers may be from a lack of understanding of palliative care or a lack of education about effective pain control. Other barriers may be seen in people who have been in health care a long time and may feel threatened by a new idea coming into their territory: “We have already been doing this.” “I don’t hear any families complaining.” Take time to listen to people, but be sure to have effective counter discussion points to present.

Being aware of the barriers in your institution and having a plan to work through or around them will help your program development. Taking time as a team to discuss this and work together to decide which battles are worth fighting and which should be left alone or kept for another day.

The PICU staff embraced the team, but wished they were more available. This was not in the budget. Yet with discussions, collaboration, and negotiations, one position was increased and a new NP position
created. Hospice home care staff were resistant “I didn’t come into this to care for kids!” Gradually pediatric care became the norm and more clinicians were willing to provide palliative care for children.

Data collection and measuring your progress

Data collection may not be a top priority for your team as you plan your program. However it is very important as you move from being a novel start up program to an integral part of your institution. It is important to show with statistics that your program is making a difference. Common data that is collected includes number and diagnosis of patients, number of contacts, family satisfaction, changes in pain and comfort scores, and length of stay. Data collection will provide you with facts that can support the need for the program as you continue to grow. Individual testimonials or comments from families speak with an authority and strength that nothing else can.

The team struggled with what data to collect, how to do it, who should be responsible etc. They asked the leadership teams what they wanted to know and started off with a simple excel sheet. It is not perfect but it is a start and made for wonderful charts and diagrams for the end of year report as the program grew!

Paying for it

The question of how to fund the program is a common issue. Most programs use a combination of sources to cover their costs. Generally speaking, program costs are covered through a combination of philanthropy, institutional support, and reimbursement. It is roughly one-third from each source. Taking time to think about this issue and to have a sound business plan is an essential part of planning your program.

Fund raisers can provide financial support for your program, but come with their own burdens and demands. However they can provide a wonderful platform to let people know you are developing a program in your community. It may not be the amount of money raised that is the most important aspect, but rather the number or supporters. At times, $300 raised by 10 enthusiastic people who will continue to tell others and bring in support is worth more than a $3,000 dollar donation by a company that sees it only as a tax write off and provides no other support.

One leading hospital foundation said “People don’t want to give money for dying children, so we don’t talk about it.” How wrong they were- another organization in the same community raised 7 million dollars for the same goal. People want to help. Do not ask people to donate to dying children, rather invite them to be part of a program that helps children live fully and joyfully, even as they face life limiting conditions. Institutional support is essential to the development and maintenance of a program. Very few pediatric palliative care programs can afford to be totally free standing. Therefore garnering of institutional support is essential. This may be in the form of allowing a link on the web site, providing a telephone line or office space, or even paying for staff. You may need to start small and grow as you can prove your effectiveness in helping your institution reach its overall goal of improved care for patients and families. Reimbursement is possible for some of the palliative care visits. In some states, both physicians and advanced practice nurses can bill the insurance companies. Find out what is possible in your state.

A brief summary of ideas for program growth and development- collaboration, flexibility, perseverance and patience- always remembering to keep the child and family in the center and to weave in fun!

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- Higginson I, Sarmento V, Calanzani N, Benalia H, & Gomes B. Dying at home – is it better: A narrative appraisal of the state of the science. Palliative Medicine, 2013; 27(10): 918-924
- Proverbs 29:18, King James Version of the Bible

**Web based Resources:**
- [www.HPNA.org](http://www.HPNA.org) – Hospice and Palliative Nurses Association, a US-based nursing organization with web based resources for professionals and families.
- [www.togetherforshortlive.org.uk](http://www.togetherforshortlive.org.uk) is a UK-based organization working to improve care and services for children with life-threatening or terminal conditions and their families. They have a list-serve, resources, etc. A searchable database for literature for the health professional is accessible through [www.act.org.uk/pages/ipp1.asp](http://www.act.org.uk/pages/ipp1.asp)
- [www.ippcweb.org](http://www.ippcweb.org) The Initiative for Pediatric Palliative Care offers a comprehensive web-site with curricula and resources, including videotapes and other helpful educational resources.
- [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics) The National Hospice Palliative Care Organization hosts the Children's Project on Palliative/Hospice Services (ChiPPS) offering NHPCO's Pediatric Facts and Figures, NHPCO’s Standards of Practice for Pediatric Palliative Care and Hospice, and a free, quarterly E-Journal on pediatric palliative/hospice care. [www.nhpco.org/i4a/pages/index.cfm?pageid=3409](http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409)
- [www.eperc.mcw.edu](http://www.eperc.mcw.edu) End-of-Life/Palliative Education Resource Center- Fast-Facts, downloadable resources relating to education about end-of-life care (not specific to but includes pediatrics), oriented for physicians, applicable to other health professionals. Will now be housed in AAHPM (American Academy of Hospice and Palliative Medicine at: [http://www.aahpm.org](http://www.aahpm.org))
- [paedpalcare@act.org](mailto:paedpalcare@act.org) A UK Pediatric Palliative Care Mailing List with a searchable database for health care professional literature.
- [www.cityofhope.org/Pfc/](http://www.cityofhope.org/Pfc/) This the City of Hope's Pain/Palliative Care Resource Center Website that Betty Ferrell has been involved in for a number of years with a large number of online resources for professionals and practitioners.
LESSONS LEARNED FROM STARTING A PEDIATRIC HOSPICE SERVICE AS PART OF AN ADULT HOSPICE PROGRAM

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Background

In 2001, I was introduced to providing pediatric hospice care as part of my role as a Home Hospice Nurse Case Manager. I eagerly accepted the challenge because I believe children and their families need as much support during this end-of-life journey as adults do, if not more. Over the next seven years, I took care of many children too numerous to count as I found out not many individuals are willing to work in pediatric hospice care. My nurse Case Manager colleagues at the time were all too glad that I took on this responsibility and basically let me do it all. The good news is that I had a fantastic mentor and resources through the CHOP PACT (Children’s Hospital of Philadelphia, Pediatric Advanced Care Team) team. The relationship developed over the seven years so that when I left to join Abington Hospice program, there was joint interest in starting a formal pediatric hospice service at Abington. Up to that time, they did accept referrals when approached, but had no formal program to be a base for referrals.

Beginning Preparations

Discussions began with the leadership of Abington Hospice to determine the steps that would be needed to put forth a case for the new pediatric hospice service. We developed a list of what information was needed to present to the senior leadership in order to gain approval for initiating and funding the program. A tip: use graduate students for this process. We were fortunate at the time to be hosting a graduate student who was very interested in helping to do all of the background research on the need for pediatric hospice services including the financial needs to run a program. Using a nursing graduate student was the best decision; as part of her administrative track, she needed this type of proposal to fill her requirements. The result was a win-win solution for all of us.

The first decision was: Do we just accept an occasional pediatric patient or go for a full program? We needed to find out that answer, as it would determine how we would proceed. Abington had been taking infants onto hospice but only rarely. Were we in for the full program as a referral source or not? We needed to establish that background as our approach would be different from the previous arrangement. The proposal presented to the senior management highlighted the need, the community mission, and the costs associated with this program. We were upfront about our expectations about the need to offset the cost of the new program, as reimbursements would not be nearly enough. Abington leadership strongly supports programs to help the community so they gave us the go ahead to initiate the plans and for Office of Philanthropy to fundraise.

Making the Process Happen

The hospice leadership met to develop a work flow plan outlining everyone’s piece to develop and complete. The attached flow chart is a sample of mapping out the steps needed, who was responsible for each task, and when each task needed to be completed. It was updated at weekly meetings. Special meetings were held when any obstacles or issues were discovered. We met weekly to assess progress and strategize any changes needed. The weekly meetings also helped to reenergize individuals and keep them on task. The key was encouraging those individuals who were really embracing the pediatric hospice concept. Everyone is busy but somehow they kept coming together and moving the process along. It was very reassuring and reaffirming that we were doing the right thing.
We also had to have nurses volunteer to take on this additional responsibility to be trained and willing to care for these children. We initially chose to go with nurses who were willing to volunteer because this work requires someone who can deal with the wide variety of challenges involved in pediatric hospice care. We knew that mandating an individual to provide this care would be self-defeating. In addition, the support that individuals need to provide this type of hospice is greater than for providing care to adults. We built in self-care, debriefing after deaths, and time in the IDG (interdisciplinary group) team meetings to review issues. Of course, the decision to accept only volunteers would have had to change if no one volunteered. We were pleased that five individuals in the field and seven on the unit came forth. The triage nurses were part of that group.

Education as a foundation was a key component for the nurses to feel comfortable and competent to take care of pediatric patients. We held two Pedi ELNEC classes for full certification within the three-month planning period and had skill-based training at the two local pediatric hospitals. Additionally, we wanted the nurses and social workers to have initial meetings for each referral at the respective hospitals and receive specific skill training relevant to each child being referred. It is difficult to maintain all of the skills with the divergent needs and limited numbers of children needing hospice care.

The process took us three months to start accepting referrals for home hospice care but another year to actually complete renovations on the unit for three pediatric inpatient beds. Since April of 2011, we have had a steady referral base of pediatric hospice/palliative care patients.

**Lessons Learned**

As with any plan or program there will always be areas that can be improved.

We learned we only needed one physician to be Medical Director. Initially, we had contacted two pediatric physicians to be Pediatric Medical Directors. We originally thought we needed 24/7 coverage, but discovered that was not necessary because of the support from the two pediatric hospitals on call. One physician had Hospice and Palliative Care Certification, was a fellow at CHOP, and had the ability to be flexible to meet the needs of the program. The second physician had acute pediatric care experience but less flexibility. We decided to start small and retain the physician with specific experience, flexibility, and credentials. We felt that the second physician would have also been appropriate as an option. Currently, we have the same Medical Director and it has worked perfectly in covering the needs. She has done home visits and attends a biweekly Interdisciplinary team meeting in addition to providing on-call services as needed. The Medical Director covers both inpatient and home pediatric patients.

The number of pediatric patients that have been and will be referred is unpredictable. It can vary by 50% on any given day, week, or month. Nevertheless, pediatric referrals are a priority and are handled by the hospice managers instead of going through intake or patient flow centers. Each case is complicated and requires upfront discussion with the referral source to address specific needs and timing.

The government program for concurrent care came into existence right about the same time our new service was implemented. The benefit was new and not always interpreted consistently between insurance providers. It continues to be struggles even today as the two benefits within the program do not match. For example, the concurrent aggressive care benefit is fee-for-service, while the hospice benefit is a per diem reimbursement service. Each insurance provider can interpret the mix of benefits as they judge best. An example was a Medicaid managed plan that did not pay the daily per diem rate while a child was in for any hospitalization. Needless to say, billing had to adjust the billing process manually to cover this. Concurrent care also brings a different focus on how hospices deliver care. Determining what is part of the hospice benefit and what is billed separately as concurrent care requires diligent discussion ahead of time if possible and with each event. The philosophy of hospice as comfort-directed care also gets blurred with concurrent care.

The team struggled at first with how to work with such divergent focus. It takes consistent redirection of the team to mentally and emotionally handle the conflicts that can arise. We found the following tips to be helpful: redirect the team to be present and allow flexibility as families navigate the two arenas; remember
to develop a caring trust with the family and child so that when the inevitable happens they turn to hospice for their support; be mindful always of what the family is dealing with and be present with kindness and compassion; remind yourself as a healthcare provider that you have always helped in some small or big way despite the outcome and/or direction the family takes. One last item is to work and collaborate with the referral source to transition care and support should it be prudent to discharge the child from care.
<table>
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| Intake Process              | LOB, Bobbi    | 4.30.11  | Initially to be handled as the current nonAMH referrals by Bobbi & coordinated with intake ofc. Bobbi to meet with S in Intake staff to review process and seek input over week of 3.28 done. Question came up re new org for pedi patients? LO to ask GB. Pedi ELNEC course 3.22 and 3.23. Repeat in May. Orientation/Mentoring month of April. Computer classes, Hospice topics, process, pedi assessments. Bobbi to set up clinical sessions thru April. Met with SW 4/12. Will work with C to send to units as schedule permits. Awaiting return email from MH at St Chris for May 17 and 18 for next pedi El nec. Each will be responsible for their area of expertise. Will start with KH and BL first to orient and train due to scheduling needs. To meet to review need to be set up.
| Orientation/Mentoring Process | Bobbi         | 4.30.11  | Child abuse clearance required. Then to PAC and appropriate further approval. After review current policies were deemed to cover taking Pedi patients with no revisions. Will be using Mosby&P&P policies for procedures as AMH does. Kim to help with comp. Will be developing process policies that do not need to go up for approval. |
| Competencies                | LOB, CMC, Bobbi, S | 4.30.11  | Hospice Pharmacia in place for home hospice. Awaiting costs of new machine and intermittent processes with angi. Need new large machine with its own computer. Then to LD for PR to process. |
| Reviewing Process with Nurses | LOB, CMC, Bobbi | 4.30.11  | 2 step process, initial by phone to CHOP and St. Chris and email with intake process then formally with brochure to area physician offices and CM. |
| Policies and procedures     | LOB, Bobbi, JD | 4.30.11  | met with Dr. AW Dr. DS and G C from legal. Contract in the process of completing. EDM to notify JK first then Bobbi to f/u with Christine. Bobbi to contact Kristine Schilling done. Came for tour on 4/8. Developing plan for rm 304 and 305. Waiting KC return from conference to complete. |
| Contract with DME           | LOB            | 4.30.11  | Decision to go with AW with appropriate credentials and flexibility. Decide to do overall education but more intense at time of referrals. |
| Brochure Page               | LOB, Bobbi    | 5.15.11  | Ofc Of Philanthropy identified donors and began fund raising. |
| Notification to referral sources | Bobbi                    | 4.30.11  | starting reviewing ways to support staff with debriefing, self care etc. |
| Notification to Abington Docs, staff | EDM | 4.30.11  | |
| Contract with Pedi Med Dir  | EDM, LOB      | 4.30.11  | |
| Furniture/design-Christine Schilling | LOB, EDM, Bobbi | 3.25.11  | |
| Computer Careplan and forms | KC, CMC, Bobbi, JD | 4.30.11  | |
| Pedi Med Dr coverage process | LOB, Bobbi   | 4.30.11  | |
| Volunteer / Chaplain Training | NL, LOB, Bobbi | 4.30.11  | |
| SW/Bereavement process      | JD, Bobbi     | 4.30.11  | |
| Renovations of Unit for 3 new rooms | LOB, EDM, Bobbi, JD | 7.15.11  | |
| Supplies, Grant Monies      | NL, Bobbi     | 4.30.11  | |
| Support for IDT Team        | LOB, Bobbi, JD | 4.30.11  | |
Developing a Pediatric Palliative and Hospice Care Program in the Community

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Introduction

For children diagnosed with a life-threatening, complex, chronic condition, and their families, community pediatric palliative care (palliative care support provided to the child/family in their home) is an integral component of care available in many areas of the country. This mode of care is designed to enhance quality of life, provide a consistent and comforting layer of support, and seamlessly facilitate transition not only from one care setting to another but also through the continuum of the child’s condition.

Friedrichsdorf et al. (2015) found that children receiving palliative care support at home while also under the care of their oncologist were “significantly more likely to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%).” As this care is generally minimally funded or unfunded, it is only through the tireless efforts and passion of those with a vision and a commitment to these children and their families that community pediatric palliative programs are established and remain in existence.

This article offers a description of the genesis and development of a successful community pediatric palliative care program serving this very specific population of children in Northeast Florida. Community PedsCare®, the pediatric palliative and hospice program of Community Hospice of Northeast Florida, in partnership with Wolfson Children’s Hospital, Nemours Children’s Specialty Care, and the University of Florida College of Medicine – Jacksonville, Department of Pediatrics, has served more than 1,000 children and their families, in their homes, throughout its 15-year existence.

The Beginning

In 1999, Florida Hospice and Palliative Care, Inc. (now Florida Hospice & Palliative Care Association) assisted in the development and distribution of a statewide survey in which Wolfson Children’s Hospital indicated that they wanted to provide better end-of-life care to their patients. The survey indicated that only a fraction of Wolfson’s patients needing this kind of in-home support were being served.

Continuing with this initial interest and evaluation, from 1999 through 2000, meetings and focus groups were held that included participation from Wolfson Children’s Hospital, Children’s Hospice International, nurse/author/pediatric advocate Sue Huff (currently director of Johns Hopkins Pediatrics at Home), and a representative from State of Florida Department of Health Children’s Medical Services.

An invitation letter was sent out to community pediatric providers and potential stakeholders in June 2000 from Susan Ponder-Stansel, CEO/President, Community Hospice of Northeast Florida and Carolyn Johnson, then Chief Nursing Officer at Wolfson Children’s Hospital, regarding the desire to develop a community pediatric program. This letter expressed, in part:

(This program) seeks to expand the traditional boundaries of hospice care and to reach all children who need care and support due to pain and symptom problems or illness. This program will serve as a model for other hospices, children’s hospitals and caring communities to replicate in their own areas. Our organizations are committed to better meeting the needs of children facing the end of life and their families, and as one who cares for and about children; we would like to ask for your help.

After the initial meeting, additional focus groups and planning continued. In January 2001, the final report stated the following conclusion:
Support for the implementation and development of a pediatric palliative care program is extremely strong. The interest in seeing the program grow was indicated by all parties. Meeting the goal of integrated service will require bringing together existing components while creating new services and processes. The opportunity exists to build on the strong interest of the parties involved.

Thus, with the bringing together of Northeast Florida’s pediatric giants and a hospice provider with the passion to provide for pediatric patients, Community PedsCare was born. This new program would provide options and services for children at the end of their lives as well as chronically ill children, to include pain and symptom management, psychological, social, and spiritual, child life, and grief support, respite care, advocacy, resource development, and education for professionals, patients/families, and the community.

Community PedsCare – Development and Successes

Fashioned after the hospice interdisciplinary team model, Community PedsCare is comprised of the full complement of critically-needed professionals required to care for children and their families—pediatric-trained and experienced physicians, nurses, social workers, clergy, child life, complementary therapies, and volunteers. Enabling the hiring of this level of staff, to ensure this highest standard of care, from its inception the program has been funded primarily by Community Hospice and the Community Hospice Foundation through the generous philanthropic support of the Northeast Florida community. Additional, critical financial, professional, and philosophical support has also been received from the program’s partners consistently over the years Providing a part-time chaplain for many years, office space since the program’s inception, and participation in funding for an inpatient physician and liaison nurse were much needed and appreciated contributions by Wolfson Children’s Hospital. Additionally, inclusion on the hospital’s palliative care committee and other appropriate committees has occurred.

In addition to this foundational funding, however, the importance of grant funding cannot be ignored—the program’s first child life specialist was possible due to a grant from the duPont Foundation. And the program is currently able to provide biofeedback as a pain control adjuvant, again, due to grant funding.

In 2004, Community Hospice was one of the first hospices in the state of Florida to participate in a Medicaid waiver demonstration project, Partners in Care: Together for Kids (PIC:TFK). Modeled after CHiPACC® (Children’s Hospice International Program for All-Inclusive Care for Children), Partners in Care’s mission is “To enable children with a life-threatening illness, and their families, to access a support system that is continuous, compassionate, comprehensive, culturally sensitive and family centered from the point of diagnosis, with hope for a cure, through the provision of end of life care, if needed.” (Partners in Care: Together for Kids, 2014). The program is collaboration between Florida hospices, the Agency for Healthcare Administration, and the Florida Department of Health Children’s Medical Services. Providing an additional source of revenue, hospice providers are reimbursed by Medicaid on a fee-for-service basis for approved services.

Through the years, Community PedsCare has grown in size, scope, program offerings, awareness, and support. It is among the largest programs in the country providing comprehensive, holistic palliative and hospice care to children and their families dealing with life-threatening conditions across the pediatric life-course, from conception through transition into adulthood. The program includes a perinatal program, community-based palliative and hospice care, inpatient pain and palliative consult service, complementary therapies, respite care, transition throughout life and condition changes and into adulthood (to age 21), parent/child support groups and activities, and memorial and bereavement services. Open to all children meeting the program’s clinical criteria within the 5-county Northeast Florida community, the program’s offerings are available regardless of financial status, with the goal of positively impacting their quality of life.

Program Development – Barriers
Development of a community pediatric palliative program, truly a benefit for complex, chronically ill children and their families, requires the philosophical and financial commitment of the supporting organization and community. Current available revenue from third party payers inadequately meets the financial needs of a comprehensive program. The providing institution’s awareness, acceptance, and understanding that development, implementation, and ongoing provision of the pediatric palliative program will require financial agreements with participating community and healthcare partners, in the broadening of partnership scope and services, endowments, grants, and strong organizational Foundation support is essential. Additionally, consistent programmatic and organizational evaluation of what is working, what’s not, and ways to increase revenue/decrease expenses must occur. Community PedsCare, through the ongoing commitment and support of Community Hospice of Northeast Florida, working in partnership with the area’s pediatric providers, has been able to serve over 1000 children and their families since its inception.

Sue Huff, in her opinion piece “Looking To Save HealthCare Dollars” (2012) notes that “some of the (other) challenges in caring for this population include: a relatively small patient volume; staffing challenges and a lack of pediatric expertise among staff; greater travel expense; longer home visits and higher number of visits per admission compared to adults.” These are real challenges that are constant. Ideally, rather than having the combined pediatric staff person’s caseload consist of both adult and pediatric patients (with primary experience being with adult care), having a unique, designated pediatric team is best. But, again, it is critical for organizational leadership and financial support to be present and on-going. Flexibility with staffing productivity related to situational needs of the child/parents/varying schedules is necessary, as well, when compared with adult care productivity.

Lastly, it has been established that quality of life is positively impacted for the children and families through the wrap-around support and services of a community pediatric palliative care program, but additional research is needed to apprise third party payers of the expected financial impact on the potential of minimizing recurring hospitalizations and decreasing length of hospital stays.

References

DEVELOPING THE INTERDISCIPLINARY TEAM IN PEDIATRIC PALLIATIVE CARE

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Introduction

Developing an effective, efficient, and compassionate interdisciplinary team (IDT) is the goal of most, if not all, hospice and palliative care organizations as it is recognized that this model of care constitutes the best care for patients and family members. Within medicine and healthcare, IDTs are often synonymous with hospice care and are one of the foundational tenets on which hospice care was founded. Hospice was started as a social model of care with an emphasis on holistic medicine and, as such, hospice is viewed as the gold standard of interdisciplinary practice in medical settings. For many years, hospice care in the United States has been regulated to require teamwork of an interdisciplinary nature (HCFA 1983). Although the IDT is a required component of hospice service delivery, the actual success of collaboration within the IDT has been reported to be quite varied (Parker Oliver et al, 2005).

Prior to identifying specific characteristics of an effective IDT, an examination of the differences between the interdisciplinary and multidisciplinary team is warranted.

Interdisciplinary vs multidisciplinary teams

A PubMed search will yield a wide range of definitions of both a multidisciplinary team and an interdisciplinary team. One of the most complete, yet clear and concise, comparison of definitions of the two models of care is offered by Rebecca Jessup (2007).

Multidisciplinary team approaches utilize the skills and experience of individuals from different disciplines, with each discipline approaching the patient from their own perspective. Most often, this approach involves separate individual consultations. These may occur in a “one-stop-shop” fashion with all consultations occurring as part of a single appointment on a single day. It is common for multidisciplinary teams to meet regularly, in the absence of the patient, to “case conference” findings and discuss future directions for the patient’s care. Multidisciplinary teams provide more knowledge and experience than disciplines operating in isolation.

IDT approaches, as the word itself suggests, integrate separate discipline approaches into a single consultation. That is, the patient-history taking, assessment, diagnosis, intervention and short- and long-term management goals are conducted by the team, together with the patient, at the one time. The patient is intimately involved in any discussions regarding their condition or prognosis and the plans about their care. A common understanding and holistic view of all aspects of the patient’s care ensues, with the patient empowered to form part of the decision-making process, including the setting of long and short-term goals. Individuals from different disciplines, as well as the patient, are encouraged to question each other and explore alternate avenues, stepping out of discipline silos to work toward the best outcome for the patient (Jessup 2007).

Although quite different in meaning, the terms “multidisciplinary” and “interdisciplinary” are often used interchangeably when describing types of hospice and palliative care teams. The strength of the IDT may originate in the single consultation model where many, if not all, team members work with the patient and family at the same time. In pediatric hospice and palliative care, engaging the child and family from the onset of care creates a strong sense of teamwork. Communication and collaboration with the child and family is initiated in that first visit, and expanded upon from that time forward.
In addition to studying the differences in these types of teams, an examination of a comprehensive definition of the IDT is also indicated to ensure optimal understanding.

**Defining the interdisciplinary team**

Drinka and Clark (2000) created one of the definitions of the interdisciplinary team that would grow to gain wide levels of acceptance by researchers and clinicians alike.

An interdisciplinary healthcare team brings together a group of individuals with diverse training and education to work on an identified task. These healthcare teams can include doctors, dentists, nurse practitioners and registered nurses, occupational therapists, pharmacists, physician assistants, physical therapists, social workers, nutritionists, and clergy. Team members collaborate to address patient problems that are too complex for one discipline, or even many sequential disciplines, to solve. At the most basic level, effective teamwork depends on the ability of members to determine the overall mission, establish shared and explicit goals, and work collaboratively to define and treat patient problems. Ideally, teams can also learn to accept and make use of disciplinary differences, differential amounts and types of power, and overlapping roles to clarify and evaluate the team's development and effectiveness (Drinka & Clark, 2000).

Drinka and Clark’s (2000) definition is inclusive of many variables that are inherent in most IDTs: the diverse training and education of team members; the importance of collaboration; complexity of patient needs and problems; the importance of members’ ability to agree upon their overall mission and develop shared goals; the team’s acceptance and utilization of individual team members’ differences and power differentials in ways that will be beneficial; and, finally, the opportunity for overlapping roles to clarify the team’s growth and development. This comprehensive definition of the IDT illustrates the many moving parts and uncontrollable components that a team must understand, embrace, and master in order to be effective, efficient, and compassionate. These variables’ importance’s warrant further clarification and discussion.

First, the issue of bringing together a group of individuals with diverse training and education, which suggests that there may be a variety of opinions regarding both team and patient needs, may present challenges between various team members. When a team is formed, it may be difficult to ensure that each individual understands and/or embraces the training and education of all others at the table. Nurses may understand the training and education of a physician, but not of the social worker, or the chaplain whose brother is a social worker may be comfortable with that professional but not with the nurse’s aide. Or, professionals may share their perception of their own self-importance which emphasizes a power differential. Others’ roles may be appreciated only after there have been ample opportunities to observe one another’s expertise in action.

Second, the definition calls on team members to collaborate to address problems that are too complex for one of them, or even several of them, to solve independently. In some circumstances, a team member may not yet recognize his/her need to work collaboratively on complex problems, thinking that he/she may be able to tackle tough problems independently and, thus, not need to work collaboratively. Collaboration around difficult patient needs or complex patient problems is likely to require patience, mutual respect, and that ever-so-precious commodity in hospice and palliative care: time.

Next, Drinka and Clark’s definition of IDTs challenges the members of the IDT to determine the team’s overall mission and establish shared goals that will enable them to work collaboratively in providing the best patient care. When the reader considers the task of developing an overarching mission and shared goals which lead to effective collaboration, the analogy of a simmering pot of soup comes to mind, where each ingredient provides a unique flavor, while all ingredients are blending to offer the robust taste that is THE SOUP. Similarly, the individual's training and education must rise to the top and offer its own unique flavor, while simultaneously blending into the simmering pot of shared flavor, or goals.

Finally, the authors refer to the disciplinary differences, power differentials, and overlapping roles that
may enhance the team’s growth and development. This description suggests a beautiful tapestry, woven together with bright threads of various colors and consistency, resulting in a work of fine art. The IDT creates its own tapestry—no two alike and each with their own rich qualities. The similarities are in the components—the social worker, nurse, chaplain, physician—but not in the completed tapestry. Just as each tapestry contains its own, unique threads, the team includes members who have learned to use the unique talents of others in new ways, while embracing the team’s power differentials and clarifying the team’s defining qualities which enable them to share roles and responsibilities.

Thus, the IDT emerges as a well-oiled machine, consisting of a variety of moving parts, but parts which move smoothly around one another to create the reality of a single machine that operates effectively. Despite knowing each individual professional’s function, the patient should only be aware of a seamless delivery of care where the “moving parts” are effective, efficient, and compassionate as they work as a single entity. Knowing what the IDT is and what parts contribute to creating the team is the first step.

Next, one needs to know how to ensure the team contains the components that are necessary for optimal growth and development of the team.

**Components of the IDT**

Nancarrow and colleagues (2013) sought to identify what, specifically, defined effective IDTs. Their research examined a systematic review of the literature on IDTs as well as the responses of 253 staff from 11 community care teams in the United Kingdom. The data sources were then merged using qualitative content analysis which led to the identification of characteristics that are present when effective IDT work is practiced. Finally, they proposed ten competencies that support effective interdisciplinary teamwork. These competencies are proposed, by the study authors, as those which illustrate an effective IDT which is functioning at a high level. Those competencies and a brief description are provided here.

- **Leadership and management attributes:** Identifies a leader who establishes a clear direction and vision for the team, while listening and providing support and supervision to the team members.
- **Communication strategies and structures:** Incorporates a set of values that clearly provide direction for the team’s service provision; these values should be visible and consistently portrayed.
- **Personal rewards, training and development:** Demonstrates a team culture and interdisciplinary atmosphere of trust where contributions are valued and consensus is fostered.
- **Appropriate resources and procedures:** Ensures appropriate processes and infrastructures are in place to uphold the vision of the service (for example, referral criteria, communications infrastructure).
- **Appropriate skill mix:** Provides quality patient-focused services with documented outcomes; utilizes feedback to improve the quality of care.
- **Supportive team climate:** Utilizes communication strategies that promote intra-team communication, collaborative decision-making, and effective team processes.
- **Individual characteristics that support interdisciplinary team work:** Provides sufficient team staffing to integrate an appropriate mix of skills, competencies, and personalities to meet the needs of patients and enhance smooth functioning.
- **Clarity of vision:** Facilitates recruitment of staff who demonstrate interdisciplinary competencies including team functioning, collaborative leadership, communication, and sufficient professional knowledge and experience.
- **Quality and outcomes of care:** Promotes role interdependence while respecting individual roles and autonomy.
- **Respecting and understanding roles:** Facilitates personal development through appropriate training, rewards, recognition, and opportunities for career development.
It is interesting to note that, within these ten recommended competencies of an effective IDT, Nancarrow and colleagues include each of the topics identified in the definition of an IDT provided by Drinka and Clark (2000). Thus, some fifteen years after the concept of IDTs in hospice and palliative care has become commonplace, the consistency in what defines an effective, efficient, and compassionate IDT has also gained consistency in definition and in practice.

**Challenges to the IDT**

It is not surprising, however, that there are challenges to the IDT even when the recommended characteristics of the IDT, as suggested by Nancarrow and colleagues, are included in the make-up of the team. Often, difficulties may arise as a result of an individual’s difficulty in understanding the importance of the requisite team characteristics. Or, perhaps a team member does not perceive that he or she is a valued member of the team. If there is a real, or perceived, power differential, the team may be experiencing a real threat to its viability. Despite growing recognition that there is a real or perceived power differential in IDTs and that this phenomenon may be used to strengthen the team, a power differential within a team may also create difficulties in how team members are perceived or how they perceive their own value.

Reese and Sontag (2001) reported practices that may undermine the IDT and offered solutions that may ensure the team’s success. Twelve potential barriers were highlighted, any of which may compromise the effectiveness of an IDT. Some of the those barriers were: lack of commitment to the team process, lack of willingness to take on an equal share of the team’s work, IDT members’ lack of understanding of one another’s expertise, role blurring, theoretical or value based conflicts between different professions, negative team norms, and administrative issues, as well as others.

One example of a barrier and associated solution was related to the perception, by other team members or social workers themselves, that social work may be viewed within hospice as ancillary or secondary to medicine. Suggested solutions included orienting the team, either at orientation or in continuing education, to each professional’s role to ensure full understanding and appreciation of each profession. A commitment to the IDT from administration, or a strong team leader, may ensure that this education and appreciation is developed.

Recent attention, in both research and practice, has been given to the potential problems that may arise in the intimate setting of a patient’s journey toward death. Both the intensity of the situation, as well as the time-limited need to build effective working relationships between professionals and patient/family members, creates the perfect storm for difficulty in maintaining a therapeutic relationship. Patients and families are often very grateful for the support they receive from the hospice or palliative care team, thus resulting in their desire to give something to the professional to express their gratitude. Boundary issues surface when professionals are faced with a “second role,” or dual relationships with clients (Reamer, 2003). Professional boundaries have the advantage of providing not only protection for the patient/family, but also for the professional (Homan, 2006a, 2006b). It has been suggested by some that self-disclosure may be beneficial in relationship development, while others warn that crossing professional boundaries creates a risk to maintaining the focus on the client (Hepworth et al, 2010). Over-identification with the client, accepting gifts from the client, or going “over and beyond” to help the client when not on duty, may be behaviors that warrant support and mentoring for the professional (Dugan Day, 2012).

Peer supervision and support can help define the team’s strength while promoting trust among team members. In addition, specific training and education regarding professional boundaries in hospice and palliative care could be an integral portion of orientation and on-boarding for new professionals (Dugan Day, 2012).

Many healthcare settings including the patient-centered medical home and family medicine clinics strive to develop true interdisciplinary models of team care. However, hospice in the United States remains one of the few medical subspecialties where interdisciplinary teamwork is regulated (HCFA 1983). Despite the
fact that the IDT model of care is required by the Centers for Medicare & Medicaid Services (CMS), there is still the sentiment, among some professionals, that IDTs are actually quite variable (Parker Oliver 2005).

Conclusion

Understanding the IDT is a first step in moving toward working on an effective, efficient, and compassionate IDT. However, one key question remains:

Why is the IDT so important?

The answer to this question originates the definition of palliative care. The Section on Hospice and Palliative Medicine of the American Academy of Pediatrics definition of palliative medicine includes the following.

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 skills and knowledge of a specialized care team that 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. (http://www2.aap.org/sections/palliative/WhatIsPalliativeCare.html, 2015).

This definition of pediatric palliative care speaks of “enhancing the quality of life for all involved” and of using the skills and knowledge of “a specialized care team that includes doctors, nurses, social workers, chaplains, child life therapists and others.” The definition goes on to include that the discipline “focuses on pain and symptom management, information sharing, advance care planning, practical, psychosocial and spiritual support and coordination of care.” This includes a wide range of professionals who are learning to work together in the best interest of children and families. Nowhere in the definition is it suggested that one professional or that only medical providers for example, will define the discipline of pediatric palliative care. It does suggest, however, that a wide range of professionals be responsible for addressing the planning, practical, psychosocial, and spiritual support of the child and family, and that they afford coordination of care.

Thus, it takes the entire IDT to provide the care that is needed when a child has a serious or complex pediatric diagnosis. Utilizing the expertise of a wide range of providers ensures that there is always someone who is attending to the challenges of the child and family. At the same time, working with other professionals provides the protective factors to help guard against boundary issues; a team member’s lack of understanding of the role of another team member, or feeling overwhelmed by a job that only one person is trained to do. Offering education and training, during orientation or within continuing education requirements, to ensure that all team members begin on the same page is essential.

Combining a clear understanding of what an IDT is, and is not; focusing on the characteristics that contribute to a strong IDT, and recognizing ways that one may increase their knowledge and expertise to be the best IDT member they can be are all strong pathways to being part of the IDT solution; not the IDT problem.

Nowhere could it be any more true than here: It takes a village to raise a child (African proverb).

At the University of Kansas Medical Center, Department of Pediatrics in Kansas City, the pediatric palliative care team includes a variety of MDs (high risk OBs, neonatologists, hospitalists, oncologists, intensivists); music therapy, child life therapy, pet therapists, lactation consultants, speech and language pathologists, occupational and physical therapists, prosthetist, nurses, social workers, chaplains and a former school teacher. The MD is usually not able to be present at the IDT meetings.
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IS YOUR INTERDISCIPLINARY TEAM COMPLETE? ENGAGE A PHARMACIST TO OPTIMIZE DRUG THERAPY

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How many of your patients receive medications while on service? Most, if not all, right?

Everyone has a role to play on the interdisciplinary team. You wouldn't expect the social worker to administer medications or the child life specialist to write a prescription. But, they are integral parts of the team. A pharmacist should be an integral part of the team as well. While all hospice programs have provider pharmacists (or pharmacies they utilize) to dispense medications to patients, not all hospice programs have a clinical pharmacist as a team member. The Centers for Medicare and Medicaid Services (CMS) require thorough medication reviews on admission and at least every 14 days while the patient is on hospice service. A pharmacist can provide that expert review, evaluating for cost-effective options, drug interactions, side effects, duplication of therapy, and many other medication-related issues.

CMS Hospice Conditions of Participation assert that comprehensive patient assessment must include “a review of all of the patient’s prescription and over-the-counter drugs, herbal remedies, and other alternative treatments that could affect drug therapy. This includes, but is not limited to, identification of the following: effectiveness of drug therapy; drug side effects; actual or potential drug interactions; duplicate drug therapy; and drug therapy currently associated with laboratory monitoring” (CoP §418.54-b6). “The hospice must ensure that the interdisciplinary group confers with an individual with education and training in drug management as defined in hospice policies and procedures and state law, who is an employee of or under contract with the hospice to ensure that drugs and biologicals meet the patient’s needs” (CoP §418.106-a1).

According to Medicare hospice regulations, hospices must “employ a licensed pharmacist; or have a formal agreement with a licensed pharmacist to advise the hospice on ordering, storage, administration, disposal, and recordkeeping of drugs and biologicals.” “A hospice that provides inpatient care directly in its own facility must provide pharmacy services under the direction of a qualified licensed pharmacist who is an employee of or under contract with the hospice. The provided pharmacist services must include evaluation of a patient’s response to medication therapy, identification of potential adverse drug reactions, and recommended appropriate corrective action.” In other words, in the inpatient setting a pharmacist is the only discipline that can provide this oversight.

Because medications play a large role in managing pain and other physical complaints during the terminal phase of life, pharmacists can be an important part of the interdisciplinary hospice team. The attending physician and hospice medical director are active participants in patients’ care, certifying terminal illness, evaluating symptoms, assessing patient medical needs and prognosis, and prescribing medications. Hospice case manager nurses are the eyes and ears of the hospice team, regularly visiting the patient, communicating with patient, family, and caregivers, and coordinating the patient plan of care among healthcare providers. Nurses assess patient symptoms and recommend and evaluate the patient’s drug therapy. The nurse, as well as the rest of the team, can benefit from the support and expertise of a palliative-care trained clinical pharmacist to assist with this aspect of care.

In this time of increased expectations and unstable reimbursement, hospices must demonstrate sound financial stewardship in order to maintain the highest quality care and support for patients and their caregivers. Given that hospice organizations must maneuver under a fixed per diem, cost-effective prescribing practice, monitoring, and follow-up are of paramount importance. As drug expenditures are second only to personnel costs for most hospice programs, pharmacists’ knowledge of cost-effective
medication alternatives can help control those costs.\textsuperscript{2}

There are many benefits of including a pharmacist in your interdisciplinary groups. Pharmacists help optimize medications regimens by assessing for potential drug interactions, reducing duplications of therapy, recommending cost-effective alternatives, and evaluating potential side effects. The pharmacist can provide education to team members regarding appropriate medication use, new drugs on the market, and pediatric-specific medication administration concerns. Avoidance of admissions to hospitals or long-term-care facilities through improved symptom control is a highly desirable and cost-effective outcome of pharmaceutical care for hospice and palliative care patients.

Some of the many services pharmacist can provide hospices include:\textsuperscript{2-3}

- Evaluate symptoms and recommend appropriate drug therapy, including cost-effective alternatives when appropriate. Guide drug therapy selection and individualize dosing using expert knowledge of drug pharmacokinetics. Recommend dosage adjustment based on knowledge of patient’s renal or hepatic status. Interpret drug serum levels and adjust therapy appropriately. All while detecting/preventing drug interactions.
- Perform accurate opioid conversion calculations, including methadone.
- Identify alternate routes of medication administration for patients with difficulty swallowing or loss of consciousness, offering extemporaneous formulations when necessary.
- Alert staff and recommend management strategies for medication recalls or shortages.
- Determine whether a specific medication is related to the admitting terminal diagnosis/prognosis.
- Offer input regarding discontinuation of medications that are no longer providing benefit based on the patient’s status. Each medication should have a therapeutic goal and that goal is likely to change over time. Determine which medications can be stopped abruptly and which need to be tapered down, giving specific directions on how quickly to taper down and what to monitor during this process (e.g., signs or symptoms of withdrawal or disease exacerbation). Elimination of unnecessary or futile drug therapy can minimize unwanted side effects and drug interactions, as well as decrease a patient’s overall “pill burden.”
- Provide continuing education to health care practitioners.

There is a scarcity of healthcare professionals with pediatric-specific training. Medication use in pediatric patients is complex and challenging, especially administration. A majority of commercially-available medications are not formulated for the routes of administration, dosing, and taste preferences specific to pediatric patients. This leads to various manipulations of adult dosage forms and increased risk for dosing errors and toxicity. A pharmacist, especially one with pediatric training, works to prevent dosing errors and toxicity by recommending appropriate formulations.

While feeding tubes are not extremely common in the adult population, they are often seen in children requiring palliative or hospice services. Feeding tubes can provide an excellent means for medication administration. However, some medications cannot be crushed, may clog feeding tubes, or may interact with feeds. Pharmacists can determine which medications can be administered via feeding tube or crushed and sprinkled on soft food, as well as provide recommendations to restore and maintain patency of enteral feeding tubes.

There are several methods hospices can use to obtain a pharmacist’s expertise regarding medication therapy management. Cost savings from more cost-effective alternatives and avoidance of drug-related adverse events often justifies including a pharmacist on an interdisciplinary team. While hospices can employ a pharmacist directly, most pharmacists who provide pharmaceutical services to hospice programs are not employed directly by the hospices but by a provider of pharmaceutical services, such as a home health pharmacy or hospital. Many are employees of pharmacies that have contracts with hospices to provide drug products and services. Numerous hospices already contract with pharmacy benefit management companies to provide medications and clinical consulting pharmacist services to each of their patients; these services can include clinical recommendations and staff education.
In many states, pharmacists can enter into collaborative practice agreements under the supervision of a physician to manage drug therapy. For example, pharmacists can assess the results of drug serum levels and adjust medication doses as needed. These pharmacists are typically part of a physician's office practice, in a hospital or nursing home setting, or even at the local pharmacy.

Pharmacists can improve the cost-effectiveness of pharmacotherapy for symptom control in hospice care through patient-specific monitoring for drug therapy outcomes, recommending alternative drug products and dosage forms, minimizing duplicative and interacting medications, compounding medications extemporaneously, improving drug storage and transportation, and educating staff, patients, and families about the most efficient ways of handling and using medications. Pharmacists offer clinical expertise, unique insights, and beneficial recommendations regarding medication use/monitoring and patient management that result in improved therapeutic safety, and humanistic outcomes, and may contribute to more cost-effective health care.4

References:


THE ROLE OF MUSIC THERAPY IN PEDIATRIC PALLIATIVE AND HOSPICE CARE

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How do you do music therapy in pediatric hospice and palliative care? This is an in-depth question, one which can best be answered with a case study. This particular case study is about a 19-year-old female with acute lymphocytic leukemia. We will call her Sandy.

Sandy had been in and out of the hospital since she was 12. She had a brief remission at age 15, but then relapsed again at 17, at which point I met her and began building a relationship with her. Sandy was initially a quiet, shy girl originally from the Dominican Republic. However, once she became familiar with you, she had a quick wit and loved to tease. She wanted to go to medical school to pursue a career as a pediatric oncologist and was also extremely gifted in the arts, including music. She played clarinet in her high school band and throughout her music therapy treatment over the next 2 years also worked on piano, guitar, writing, and singing.

Initially, Sandy’s coping skills were well-polished. This assessment was formulated from a compilation of information from nursing staff, her family, and her medical charts: she seemed to be handling her relapse well. At first, due to her shyness, the therapeutic approach did not include engaging Sandy in music therapy. Rather, considerable time was spent between the music therapist and the patient, purposefully building a relationship. Music therapy is a profession that most people are unfamiliar with, so building a relationship and trust with patients before initiating therapy usually leads to the most successful outcome (Robb, 2000).

We talked about school and her interests, and visited during art projects. One day she asked if she could play the keyboard. Immediately, the keyboard was set up in her room and she began to learn a song that she enjoyed and requested to learn. She learned several songs on the keyboard and guitar throughout her treatment. Initially, she enjoyed the challenge involved in reading sheet music. However, as her treatment continued and her health diminished, reading sheet music was too taxing and she required the notation and instruction to be simplified a great deal by the music therapist. When teaching Sandy how to play an instrument, the goal was always to develop this skill as a coping strategy for her; a tool she could always use to help her work through her problems, express how she feels, or “escape,” depending on what she needs (Barrickman, 1989). In order to support that goal, the music was adapted to meet her needs (Kusch et al., 2000).

As her treatment became more complicated, she began to miss school and friends. Her illness progressed and she became weaker. When she was in the hospital, Sandy often could not or would not get out of bed. As a result, Sandy became very isolated. At this time, the goals in the music therapy sessions were not only to support coping and expression, but to provide Sandy with some socialization. In order to meet these goals, music therapy treatment was provided in concert with the Child Life Specialist to provide group support, in addition to individual therapy (Robb, 2000).

After Sandy’s final relapse, her treatment and illness created a great deal of pain for her. Pain and isolation often led Sandy to exhibit symptoms of depression and anxiety (Kaplan, Busner, Weinhold, & Lenon, 1987). There were many days throughout her treatment when she was either unable to do anything or refused. That was when the music therapist brought a guitar and songbook into her room and just played for her. If she would participate, the music therapist talked her through various pain management techniques and imagery (Abeles & Chung, 1996). Some sessions consisted of a request to communicate with the music therapist, in whatever manner she could, to indicate if she did not like the music being played. This provided Sandy with some feelings of control, aimed at helping to alleviate...
symptoms of depression (Robb, 2000). Most music played was patient-preferred songs (Gfeller, 2002), which were adapted to decrease volume and tempo (Silverman, 2014). This is one of the benefits of using live music during music therapy sessions, versus recorded music. Sandy began requesting these sessions when having extreme pain; they visibly helped her slow down her breathing and she appeared to release tension held from pain (Kallay, 1997).

When her pain was controlled and she had more energy, the sessions again focused on writing and recording songs with her. Although she was not on hospice, she was critically ill and allowing Sandy to start working on her legacy became an important goal (Daveson & Kennelly, 2000). Sandy created several music videos with the music therapist throughout her treatment, with the therapeutic purposes of gaining some control in the hospital, developing coping skills, as a form of expression, and to better communicate with friends, family, her medical team, and other chronically ill teenagers. The first music video was simple and was created while she waited for a lumbar puncture, or spinal tap. She was without family and anxious in the procedure room. The music therapist engaged her in recording several short, three-second video clips of her medical staff. The videos were then uploaded into a program that mixed them together to make a music video. This allowed her to have some control over the medical team, took her mind off of the procedure, and made her (and her medical team) laugh and relax (Aldridge, 1983).

The second video was created during her second bone marrow transplant. Sandy was provided with a book called “Hang On, Hester” that depicted a little girl who was almost swept away in a flood. The towns’ people ran after her and kept yelling for her to hang on. Hester hung on and was rescued and in the following weeks, received mail from strangers all over the world. They said they heard her story, and her courage helped them hang on and get through their own difficult situations. Sandy enjoyed the book so much she decided to orchestrate it with instruments and record it to upload to the pediatric music therapy YouTube channel. She said she wanted it to be as much of an inspiration for other kids and teenagers with chronic illnesses as it was to her.

Sandy’s third video was made around the holidays. Sandy recently overcame toxoplasmosis, which nearly took her life. To the surprise of everyone around her, she pulled through and was about to go home. Before discharge, she was working on using playing music as a coping skill. During one session, she decided to learn “We Wish You A Merry Christmas” on the xylophone. She wanted to record it and send it to her medical team as her musical holiday card and thank you.

As demonstrated by Sandy, music therapy can be a support to patients with a wide variety of goals and needs in hospice and palliative care. Two imperative elements to music therapy are the relationship built between the therapist and patient, and the therapist’s ability to adapt the music to meet the patient’s needs (Potvin, Bradt, & Kesslick, 2015). Throughout Sandy’s treatment, every admission consisted of a new assessment of her needs, and her treatment was structured based on the assessment. Over the course of two years, Sandy used music therapy for coping, pain management, and relaxation, to increase feelings of control and enhance self-esteem, for procedural support, and to support communication, expression, and socialization (Robb, 2000). During Sandy’s final days, she was no longer able to communicate, but music therapy was there to support her family. Her mother went during Sandy’s final music therapy session, but exclaimed that she found comfort knowing that her daughter enjoyed the music. The music therapist encouraged Mom to talk to Sandy and play her favorite songs, despite Sandy’s inability to communicate back. After a few songs in the final session, Mom went to Sandy, held her in her arms, and told her that she loves her and that she does not have to worry about her family. Sandy is no longer in pain, and her family and friends will forever have her music videos, recordings, and favorite songs to keep and help carry on her legacy (Sacks, 2008).

Resources

THE ROLE OF THE SPEECH LANGUAGE PATHOLOGIST IN PEDIATRIC PALLIATIVE CARE

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Early in my career as a Speech Language Pathologist (SLP), I was extraordinarily lucky to present on the role of the SLP in Palliative Care in conjunction with an exceptional Palliative Care Physician. I thought myself at that time more informed than my average colleague on this topic. Yet, I still balked when she suggested the sub-title for our presentation, "It's About Helping Your Patients Live!" How could a physician who was a subspecialist in Hospice and Palliative Medicine not realize how disrespectful this sounded to the very patients we were trying to help? Now, ten years later I think back to this moment with humility and embarrassment, and share it now only to emphasize how deeply we can become engrained in our "traditional" roles. I was so engrained in my traditional role that at that time I couldn't see that my role IS to help the patient live, live their best life as defined by themselves, for as long as they do live.

My traditional roles as an SLP guide me to maximize function, maximize socialization, and reduce impairment for the patients I serve (WHO, 2012). While my roles as an SLP in Palliative Care are similar, they are provided in a different context. When a patient has difficulty communicating, I might attempt to habilitate verbal communication. When a patient has difficulty swallowing, I likely make recommendations for the least restrictive diet to minimize risk for aspiration, and then attempt to habilitate the swallow. When someone is facing a chronic and/or life-limiting illness, I still have a role; however, this role may become more compensatory in nature, rather than habilitative (Roe & Leslie, 2010). I can still perform my traditional roles as described; however, in the palliative care setting, these roles are more guided by the context of patient status, designed to add comfort to the patient’s quality of life, address the needs of the patient as well as those of caregivers, and it is further imperative that I ensure everyone on the team is aware of the communication and dysphagia plan (Pollens, 2004; Pollens, 2012).

There are few articles in the literature covering the role of the Speech-Language Pathologist in Pediatric Palliative Care; however, Pollens has described our specific roles: to evaluate, treat, consult, and collaborate with patients, families, and the palliative care team regarding swallowing, communication, and cognitive communication skills (Pollens, 2004; Pollens, 2012).

This description doesn't sound much different from what I would do in an inpatient hospital setting with a patient facing an acute injury/illness, from which full recovery is expected: medical history, patient (when appropriate) and family interview, physical evaluation, clinical evaluation (Arvedson, 2008). However, clinical interpretation and recommendations in a palliative setting must be made more in the context of the patient's illness and status, patient and family wishes, and quality of life as defined by the patient, and/or family/caregivers when appropriate, especially when addressing dysphagia. As an example, if I complete a clinical dysphagia evaluation in an acute inpatient setting and no overt signs/symptoms of aspiration are identified, this would likely result in discharge of my services. However, what if this evaluation was conducted on a patient with a degenerative disorder? I would be remiss to discharge this patient without a discussion and educational session about the signs and symptoms of aspiration, as the patient may experience increasing dysphagia as the illness progresses. This discussion may further include potential dietary consistency changes and potential compensatory strategies to attempt when difficulties do arise.

An additional example would include conducting an evaluation on a patient in which overt clinical signs and symptoms of aspiration are identified. In an acute hospital setting, my next recommendation would
typically be an instrumental swallow evaluation, either utilizing radiation to conduct a video swallow evaluation or passing a scope through the nare to conduct a Fiberoptic Endoscopic Evaluation of Swallowing (FEES). However, should a patient or caregiver in the context of palliative care choose to decline further testing, the wishes and goals for quality of life would then lead to a discussion. This discussion would include the identified signs and symptoms of aspiration, potential etiologies for the suspected aspiration, and identification of potential compensatory strategies which may alleviate discomfort associated with aspiration (e.g., coughing/choking), while not focusing on eliminating the aspiration. Examples of compensatory strategies can include food/liquid consistency changes (e.g., thickened liquids, softer and more cohesive foods), head/body position changes (e.g., chin tuck, sitting upright for adequate trunk support, and head/neck alignment), and additional strategies (e.g., alternating consistencies, double swallows). In addition to potentially reducing aspiration events during meals, these strategies may reduce the discomfort sometimes associated with aspiration, including coughing and choking. If discomfort with eating and drinking is decreased, we might also be able to increase nutrition and hydration, as well as increase the socialization of mealtimes.

Of course, having a conversation about dysphagia, aspiration, and potential negative sequelae of aspiration, as well as options, is typically difficult and complex. There is never any "one right answer." Each plan must be individualized and generated by the entire palliative care team, to include the patient when the patient is able to speak for himself/herself, and always including caregivers, either to support the patient in decision making, or to make decisions for the patient when the patient is not able to speak for himself/herself (Roe & Leslie, 2010; Miller & Willging, 2012). When a dysphagia plan can be generated and communicated to everyone in the child’s life, we stand the best chance to consistently assist the child in living his or her best life.

We can also assist children who are having communication issues. Children facing chronic, potentially life-limiting illnesses may have neurologic issues, or may be significantly weak from their illness and/or treatments. These factors can affect swallowing, as described, but may further impact a child’s ability to understand language, as well as the ability to express themselves. Working with children and their loved ones on communication strategies can allow children to be more involved in their own care as appropriate, as well as remain involved with and connected to family and friends. Again, one of our most important roles is education of all members of the palliative care team, which may also empower physicians to directly include the child. Research shows that children who are informed of relevant health information report less pain and anxiety than do peers who are less informed (Christiano & Tarbell, 1998; Costello, 2009).

It's easy in my profession to think that a child who is receiving palliative care is not appropriate for the services of a speech language pathologist. We might in fact think that our services are not in line with, and may be distracting from, giving someone facing chronic illness or end-of-life issues the best quality of life. The fact is that Speech Language Pathologists can play a very important role for children receiving palliative and hospice services. We can provide increased socialization, help to empower children and caregivers to be an active part of the care plan and increase comfort at mealtimes, which may also increase nutrition/hydration and socialization/engagement. These may constitute some of the most significant times for children and families at the end of life; times when they come together around a favorite meal and share the unique memories of their family.

Finally, speech and language therapy can play a very important role in providing information to the entire team about how we can all assist the child to live his or her fullest life, as defined by the patient and caregivers.

After all, as I have thankfully come to realize, it IS about helping your patient LIVE!

References


• John M. Costello (2009, December). Last words, last connections: How augmentative communication can support children facing end of life. *The ASHA Leader, 14,* 8-11


READERS’ CORNER

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Summary: A lack of trained pediatric palliative care (PPC) workers worldwide contributes to the limited availability of PPC services in both developed and low resource countries. Utilizing primary care services to provide PPC via the medical home model has been advocated to meet public needs while limiting cost and improving quality. Care coordination, child/family centered care, and attention to the mind, spirit, and body are elements of both PPC and the medical home model suggesting that these models could work collaboratively to improve outcomes. Basic care coordination, pain/symptom management, and supportive care would be provided in the primary care medical home. Specialized PPC providers would provide specialized services not available in the primary care setting, such as complicated pain/symptom management and bereavement support. This model would support integration of care from diagnosis through end of life while reducing the demands on scarce PPC providers. Effective communication and education are necessary for such an integrated model of care. The health care delivery system in the United Kingdom is an example of such an integrated model of care with seamless transitions of care from the primary care medical home to the PPC team. This approach has the potential to improve delivery of care and outcomes and will ensure that the child receives palliative care throughout the course of their life-limiting condition.

Who is the audience for this information? All providers who care for children with medical complexity, subspecialty PPC providers, and public health professionals will be interested in integrating PPC and the primary care medical home.

What is special about this article? This is an idea whose time has come. It is not a new idea, but there is more momentum towards implementation. With this integrated model, fragmentation is minimized and basic palliative care is provided in the primary care setting. While additional education and support by PPC subspecialists is needed, this is something that is very consistent with the long-standing concept of the pediatric medical home. Palliative care = good quality care!

Where and how can I apply this information? Primary care providers should identify sources of PPC education and collaboration with subspecialty PPC providers. They should establish reliable means of communication and documentation. Professional pediatric organizations and palliative care groups should work internally and collaboratively to ensure quality PPC care for all children from the point of diagnosis through death and bereavement.
READER’S CORNER

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Summary: In this article, the authors review the model of care provided by the North Carolina Child Health Accountable Care Collaborative (CHACC) for children with medical complexity (CMC). This model focuses on establishing a community-based medical home and coordinating care to provide quality, consistent, and cost effective care. Pediatric nurse or social worker care coordinators complete a child/family needs assessment, develop a care plan, refer to appropriate community services, educate the child and caregivers, and facilitate transitions by collaborating with providers and caregivers. Providers have access to the care plans via a secure web-based provider portal supporting consistency of treatment across providers and treatment sites.

Who is the audience for this information? Community and subspecialty providers of care for children with medical complexity (CMC) and those involved in public health will benefit from the description of the components of this model of care and strategies to identify the target population.

What is special about this article? The approach of CHACC in developing this model is a lesson to other such programs, especially those in the formative process. There is information about identification of CMC, appropriate access to subspecialty providers, and ongoing efforts to develop guidelines for primary care evaluation, management, and referral as well as educational material for the child and family. Data on over 1500 enrolled CMC provide an opportunity for evaluation of quality and cost information. Preliminary data support improved quality of care with reduction in length of stay for ventilator-dependent children, a reduction in readmission post hospital discharge, and a reduction in emergency department visits. The experience with CHACC has prompted the authors to call for development of more tools for predictive analysis and risk adjustment for CMC and for subspecialty referral management.

Where and how can I apply this information? The process by which this model was developed was collaborative involving many funding agencies, providers, and academic organizations. If you are a provider advocating for consistent coordinated care of CMC or an administrator interested in quality, cost effective care, the model used by CHACC provides a starting point and some preliminary data.

The article is available on the journal website:

**Summary:** In this 2-page article, the authors concisely describe two-way communication between providers and the child/family dealing with life-limiting illness. The list was triggered by a query by the past president of the Canadian Paediatric Society: “Is there a list of the top 10 or so issues an MD should think about and consider bringing up with the child/family when seeing a child with a significant chance of dying?” The list was compiled with input from Canadian pediatric palliative care providers from across Canada.

The issues that should be considered in the conversation include:
- Information about the child
- Understanding of the medical condition
- The family's preferred communication style
- Hopes and specific goals
- Bothersome symptoms
- Biggest concern/worry currently and for the future
- Siblings' understandings, concerns, and behaviors
- Financial issues
- Plan for home support services
- Faith, religion, culture issues
- Preferences for medical care and treatment
- Unaddressed questions or issues

A case is presented to illustrate the benefits of the conversation

**Who** is the audience for this information? This pretty much applies to everyone who is reading this E-Journal!

**What** is special about this article? While these questions are not novel, they are presented in a very user-friendly manner and provide a template that is easy to use and adapt especially for those unfamiliar with such conversations. Those who rarely care for children who may die or those who struggle with the conversation can follow this structure. THERE ARE NO EXCUSES FOR AVOIDING THE DISCUSSION!

**Where** and how can I apply this information? A conversation or more likely series of conversations, similar to this should be an integral part of care for children with life-limiting conditions. The conversations should begin shortly after diagnosis of a life-limiting condition and be tailored to the child’s phase or trajectory and should be revisited periodically.
ITEMS OF INTEREST

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

1. NHPCO PALLIATIVE CARE ONLINE RESOURCES AVAILABLE. NHPCO has a variety of palliative care resources available at [www.nhpco.org/palliativecare](http://www.nhpco.org/palliativecare), including:
   - Community –Based Palliative Care
   - Legal and Regulatory Resources
   - Webinars and Courses
   - Plus more for NHPCO members

2. NEW NHPCO PEDIATRIC PALLIATIVE & HOSPICE CARE FACTS AND FIGURES AVAILABLE. The [2015 version](http://www.nhpco.org/palliativecare) provides an overview of pediatric hospice and palliative care for providers, policy makers, funders and the media. Read NHPCO’s press release for more information.

3. TJC NEW STANDARDS FOR PALLIATIVE CARE CERTIFICATION. The Joint Commission published New and Revised Standards and Elements of Performance (EPs) for Palliative Care Certification effective for Palliative Care Centers, July 1, 2015.

4. PEDIATRIC HOSPICE AND PALLIATIVE CARE RESOURCES:
   - A new Spanish language brochure from the National Institute of Nursing Research (NINR) is available and shows how palliative care can help children with serious illnesses and their families. Read the press release.
   - Comprehensive Cancer Care for Children and Their Families: Summary of a Joint Workshop by the Institute of Medicine and the American Cancer Society (2015) is available to download online.
   - Helping Children Who Need Palliative Care to Access Education: A Resource for School, Colleges, and Early Access Providers was published by Together for Short Lives (in England). Request a free download here.
   - 7 Unusual and Wonderful Books that Help Children Grieve and Make Sense of Death, from Japanese pop-up magic to Scandinavian storytelling to Maurice Sendak, offer a gentle primer on the messiness of mourning and the many faces and phases of grief. Learn more.
   - New from the American Cancer Society: Putting Quality of Life in Prime Time: Palliative Care Resource Guide.

5. Journal / News Articles:
   - Meet the Incredible Groups Helping Families in Their Darkest Hours, Huffington Post (10/09/2015); read article.
   - Seattle Nurse Vows to Create Region’s First Hospice for Children, KomoNews.com (10/22/2015); read article.
   - Alleviating Pain, Delivering Love, New York Times (9/6/2015); read article.

6. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL. For upcoming E-Journal issues, we plan to address issues related to: a starter kit or “how to” tools for new programs in pediatric palliative/hospice care, and respite care. 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 christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!
7. **READER’S CORNER.** Our Reader's Corner columns, like those in this issue, 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.

**HAPPY HOLIDAYS!**
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-Journal 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, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.