Newsletter

March 2014

Section on Hospice and Palliative Medicine

From the Chair

Brian Carter, MD, FAAP
Kansas City, MO

Can Palliative Care Solve the Problem of Providing Complex Chronic Care for Children and Youth With Special Health Care Needs (CYSHCN)? Should it?

The medical home model for pediatrics is predicated on the logic that pediatricians who know their patients’ health care needs best are in the position to orchestrate and provide the multiple levels of primary, specialty, rehabilitative, and supportive care necessary to meet the needs of CYSHCN and their families.[1] As pediatricians continue to evolve their practices and construct functional medical homes, there remain challenges in addressing those children and youth who are often in and out of tertiary children’s specialty hospitals, subspecialty clinics and numerous rehabilitative and supportive care clinicians’ offices. Across the age spectrum, perhaps as many as 10 million children in the US have “special health care needs” and many may not be in receipt of all of the services they need.[2]

What portion of these children might stand to benefit from the attention and follow-up of an interdisciplinary palliative care team? How many medical homes utilize palliative care services? Further, when CYSHCN are seeking acute care, might such a visit present a timely opportunity to make such a referral or serve as a touch-point for those already being followed by palliative care?

The utility in providing robust services to CYSHCN in the medical home might be worthy of study in local settings as pediatric palliative care teams work to find acceptance and demonstrate value in acute care settings. Certainly, these children often fail to obtain the services they need across many chronic care settings – be they premature, managed on home tracheostomy or assisted ventilation, or with conditions such as spina bifida, cystic fibrosis or cerebral palsy.[3] And some evidence exists to support the idea that pediatricians might be more inclined to increase the number of CYSHCN in their practices if they had additional supports.[4]

In the acute care children’s hospital with a palliative care service, what role might be played to enhance or enrich the medical home? If the de facto medical home appears to be the multispecialty clinics in a children’s hospital, and the primary pediatrician’s role is diminished, *should* the palliative care service assume some overarching coordinating role? Should it be the voice of continuity and advocacy for the “whole child” and knit together what might otherwise be fragmented organ or disease-specific care? Should it partner with primary care

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providers to enhance their ability to coordinate care? The answers to these questions will certainly require further deliberation, and most likely be determined by contributions from hospital leadership, community pediatricians and state AAP chapters, potential payers and advocates for children – both parents and professionals. I invite you to this conversation.

Respectfully,

Brian Carter, MD, FAAP
SOHPM Chair

References

1. McPherson M, et al. A new definition of children with special health care needs. *Pediatrics* 1998;102:137-40.
2. National Center for Medical Home Implementation – accessed at: http://www.medicalhomeinfo.org/how/care_delivery/cyshcn.aspx
3. Conrey EJ, et al. Access to patient-centered medical home among Ohio's Children with Special Health Care Needs. *J Child Health Care* 2012;17(2):186-96.
4. Agrawal R, et al. The capacity of primary care pediatricians to care for Children with Special Health Care Needs. *Clin Pediatr* 2013;52(4):310-14.

Addressing the Challenges of Introducing Palliative Care to Families

By Katie Bucklen, MD—*St. Louis, MO*

Even before becoming a palliative care provider, I understood that most parents and families of children with critical or complex illness are frightened of having their doctor 'give up' on their child. When a child's illness is extraordinarily rare, complicated or devastating, it is natural for parents to hope against hope that *their* child will be the one to overcome their illness and survive well. With or without medical training, parents rely on their child's physician to join them in this hope.

It can be a challenge when the suggestion of a palliative care consultation is taken as a sign of 'giving up' by a parent. Because of this fear, or fear of any misunderstanding of intent, introducing the idea of palliative care (PC) is challenging. And while it is a great pleasure to have calls from residents who have witnessed and ascribe to the benefits offered by PC, it is often clear that the intern making the call has no prior experience of PC, or worse, there are undertones in their summary of the case that indicate misgivings about the choice to consult the palliative care team at all.

Yet every palliative care provider knows that working together with teams who are at varying levels of acceptance and understanding of PC requires clarity of purpose and support similar to that we seek to provide for families and patients. If we wish to truly educate trainees, and to offer families autonomy in choosing whether to meet the palliative care team, then they should be the ones to introduce the topic of PC consultation. But when I tell residents that the primary team needs to present the idea of consultation, they often express anxiety about how best to bring the topic up to the family. The desire to minimize the risk of misunderstanding is high. Fear of broaching this difficult subject seems tantamount to delivering bad news.

After repeatedly guiding residents with words for introducing the idea of a PC consultation - such as suggesting avoiding the words "palliative care" in order to avoid any misconceptions regarding intent, while emphasizing support for decision making, assistance with goals of care and communication with consulting services – we finally came up with a script that we printed up. We offer the text to the residents or staff who are uncomfortable introducing palliative care. It reads as follows:

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> *"As part of providing the best care for your child, we'd like to involve the Pediatric Advanced Care Team. This team specializes in asking the right questions to help us better understand the goals you have for your child as well as your family, and how these goals can guide the other members of the medical team. They serve as part of the team caring for your child every time he/she is in the hospital and wherever he/she is admitted. In this way, we make sure all our medical decisions are in line with your goals of care for your child."*

Since developing this script we offer it to residents and faculty who call us to request a consult. The most common reaction to this information is visible relief, which is then followed by increased confidence going in to patient rooms to introduce the idea of consultation. Even faculty and residents who are more experienced introducing PC consultation have voiced appreciation of a somewhat standardized presentation as a reference point. Even with the script, there is still some variability in the understanding of PC when we ask families on meeting them at the time of consultation. On the whole however, there has been little evidence of gross misunderstanding.

There are likely as many solutions to this issue as there are pediatric palliative care teams. How has your team worked with primary teams to improve the experience of introducing palliative care consultation, to decrease the fear of being perceived as giving up, or reluctance to ask for consultation because of concerns about misunderstandings? It would be most interesting to learn from other's experiences in this regard and encourage using the listserv to write about particularly helpful techniques for introducing palliative care at your institution so that all may benefit.

Integrative Medicine and Palliative Care

By Ana Maria Verissimo, MD, MA, ABIHM, FAAP—*Hartford, CT*

Palliative care and integrative medicine have similar philosophies focused on the importance of the mind, body, and spirit in unison with the patient's support system and community. The landscape of pediatric palliative care offers the opportunity for providers to introduce a variety of integrative medicine therapies that may facilitate health and healing for patients and their families. This is particularly true in the context of symptom management. Certain integrative medicine modalities have a substantiated and promising basis for alleviating distressing symptoms such as pain, anxiety, nausea and poor sleep. Therefore, these therapies should be available in order to support patients and their families at this most delicate time. Some examples follow.

Pain is influenced by developmental stage, prior experiences with pain, anxiety, and other physical and emotional stressors, in addition to the patient's innate temperament. Unfortunately, many studies indicate that there is sub-optimal pain relief during the last days of life. The need to improve pain relief and decrease distressing symptoms including nausea, poor sleep, dyspnea, and anxiety is far-reaching. The ability to achieve this goal affects not only the patient, but all those involved with the patient's care. Pain assessment can be done using well established pain scales that are developmentally appropriate.

In addition to use of traditional medicine, it is well established that non pharmacologic supportive modalities play an integral role in pain management. These may include physical touch such as swaddling, rocking, massaging, and application of warm or cool compresses. The use of transdermal electrical nerve stimulation (TENS unit), physical and occupational therapy may also provide pain relief.

Massage

To my knowledge there have been no pediatric massage therapy studies conducted for children in palliative care. However, we can postulate that this may be an effective treatment given pain reduction in adult studies. There are encouraging results in pain relief from massage therapy for children with a variety of chronic illnesses. However, the studies have been of small sample sizes, varying massage sessions, and individuality of treatment (i.e., frequency, depth of massage, duration of session, use

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of aromatherapy, type of massage and placement of massage). They have also been non-blinded studies with no control group. In addition, studies should include parentally delivered massage if possible. This may defray costs while also advancing the greater goal of enhanced healing for the patient and family member.

In a 2007 analysis of several randomized, controlled trials of pediatric massage, Beider and Moyer found that massage therapy can be useful to decrease pain and anxiety in a palliative care setting. Massage therapy can also provide comfort through touch. The authors emphasize, however, that massage therapy at end-of-life needs to be gentle and mindfully focused on patient's needs and those of the family.

There certainly seems to be a place for pediatric massage in the palliative care treatment plan. The application of "gentle, compassionate touch" for end-of-life symptom management and healing seems to be indicated. Furthermore, empowering the patient's family by learning and providing "touch therapy" to their loved one has immense value.

Clinical Aromatherapy

Clinical aromatherapy is the use of plant essential oils by qualified providers in order to improve healing and/or treat disease. The integration of aromatherapy in the hospital setting, either with massage or independent of massage, is considered safe. In addition there is growing literature, primarily in adults, suggesting its benefit in decreasing anxiety and pain, and promoting restorative sleep. In a study of 288 adult cancer patients who were randomly assigned to aromatherapy massage and usual care, Wilkinson found a significant decrease in anxiety for up to two weeks after the intervention. However, no long term benefits were found. There are limitations to the studies thus far, however, including small sample size and combination with massage treatments and variety of essential oil blends.

Mind-Body

Mind-body techniques such as diaphragmatic breathing, guided imagery, cognitive behavioral therapy, hypnosis, biofeedback, and distraction are well supported in the literature for pain relief. Furthermore, these techniques have virtually no side effects and promote self control with active participation in patients' medical treatment plans. These are also therapies that families can implement for their child, thereby enabling members of the patient's support system to become "active" participants in the healing process. Randomized controlled trials by Uman et al found that hypnosis may alleviate pain and anxiety in needle related procedures. They also found that hypnosis reduces the incidence of chemotherapy induced nausea and vomiting.

Art Therapy

Art Therapy is a complementary therapy that focuses on the premise that producing art can enhance the healing process. It is used to increase a patient's self awareness, ability to cope with distressing symptoms, and ability to adapt to stressful situations. It provides a means whereby patients can increase self esteem and sense of control. The theory implies that through the process of making art, a person can express emotions that are difficult to articulate. Research in this field is growing, and suggests that art therapy may improve adverse symptoms seen in adult and pediatric oncology patients.

For example, in a study involving 50 adult hospitalized cancer patients who participated in one hour of art therapy, ninety percent of participants stated the art therapy session distracted them and allowed them to focus on something positive. The Edmonton Symptom Assessment Scale (ESAS) and the Spielberger State-Trait Anxiety Scales (STAI-S) were used prior and immediately after the art session. There were improved symptoms in 8 of 9 measured categories using ESAS scale and improvements in most areas of STAI-S. The researchers were surprised to find that there was an improvement in "tiredness" after the 1 hour art session. Most patients described feeling tired at baseline, but some patients reported feeling "energized" after the session. Despite several limitations, this study will hopefully encourage future research on the effects of art therapy for chronically ill patients.

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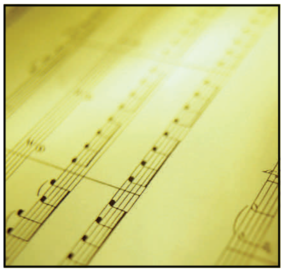
Music Therapy

There is a growing body of literature that advocates the benefit of music therapy within a children's hospital. The available research suggests that music therapy may decrease anxiety and pain. In addition, it encourages the patient to express themselves through music. Musical expression can provide a therapeutic release of emotions within a supportive environment. Furthermore according to Aagaard, children's songs "were interplays of loveable acts between patients, parents and music therapist." One can imagine how powerful this therapy can be to provide support in the grieving process.

The potential of integrative medicine in the palliative care setting is for patients to develop coping skills and to regain a sense of control and empowerment in their treatment. In addition, it offers the opportunity for the patient's family and support system to contribute to the care of their loved one. I believe Integrative Medicine favorably contributes to the healing process, particularly in the palliative care setting. It should therefore be discussed and encouraged at diagnosis.

Selected Readings

- Buttle, S et al. Commentary Massage for pain relief in pediatric palliative care: Potential benefits and challenges. Pediatric Pain Letter 2011;13:24-29.
- Beider S,et al. Pediatric Massage Therapy: an overview for clinicians. Pediatric Clinics of North America 2007:54:1025-1041.
- Fitzgerald,M and Halcon,L. A Pediatric Perspective on Aromatherapy. Integrative Pediatrics by Culbert T and Olness K. (2010), New York:Oxford Univ. Press, 123-145.
- Wilkinson,SM et al. Effectiveness of aromatherapy massage in the management of anxiety and depression in patients with cancer: a multicenter randomized controlled trial. Journal of Clinical Oncology 2007;25:532-9.
- Uman, L et al. Psychological interventions for needle related procedural pain and distress in children and adolescents. (2007) The Cochrane database of systemic reviews, the Cochrane Library, the Cochrane Collaboration.
- Nainis, N et al. Relieving Symptoms in Cancer: Innovative Use of Art Therapy. Journal of Pain and Symptom Management 2006;31:162-169.
- Lindenfelser,K. Parents Voices Supporting Music Therapy within Pediatric Palliative Care. Voices: A World Forum for Music Therapy 2005;5: No 3.

Section Seeking Parent Affiliate Members

The SOHPM is seeking parents to join as non-professional affiliate members to bring their knowledge and perspective to the Section and its activities. Specifically, we are looking for parents/primary caregivers of children affected by life-threatening conditions who you think would be interested in the mission and activities of the Section, especially promoting pediatric palliative and hospice care.

Benefits of affiliate membership include:

- Adding one's voice to the conversation about pediatric palliative and hospice care, including helping providers understand the spectrum of families' needs and experiences.
- Helping our professional community influence and advance the field of pediatric and hospice care, including building national awareness
- Participating in rich conversations with pediatric palliative care professionals
- Receiving the Section's quarterly e-newsletter containing articles from doctors, social workers, nurses, and fellow parents
- Submitting articles or other content to the Section's e-newsletter and other section educational or informational materials
- Opportunity to participate in the Section Parent Advisory Group* to help the Section realize its strategic goals

  *Note: The Parent Advisory Group is currently open to interested mothers and fathers (including foster or kinship parents). Potential members may be required to meet additional eligibility criteria.

Parents can apply for affiliate membership here. Please encourage parents you think would be interested to apply. Parents will need a letter of support from a professional SOHPM member.

Diary of Dying

By Kerri Rezendez—*Grafton, MA*

July 2011

The first chemo day was really hard on me. This was the final step that made this real. Kai has cancer. This is our life now and chemotherapy is the best option we have to help him, which all seems so wrong. He has been breastfed and eaten only organic fruits and vegetables up to this point and now I am supposed to bring him week after week and sit back as the doctors and nurses pump him full of poison, watching him get sicker by the minute, hoping that one day this will all somehow make him better? Hoping in the end this will save his life…

March 2012

Last week Kai had his routine 3 month MRI. They said the tumor looks 'exactly the same' as the last MRI. They have said that this protocol is 'not intended to shrink the tumor' but to keep it from growing, but as I have talked to other optic glioma families, I have not met one that had NO shrinkage— I have heard they all had shrinkage right away and in some cases the shrinkage was significant. But not Kai, Kai is stable. The team sensed my frustration for Kai's continued decline. We spent hours going over the things that were worrying me. I told them how his vision seems worse. He is very unstable when sitting, listing to the right, rocking and shaking. He can barely get his hand to his mouth to feed himself. He is also having trouble swallowing. Again I questioned, 'Could these be signs of tumor growth?' 'Is it the effects of chemo toxicity?' 'Could it be a neurological change unrelated to tumor growth?' Everyone seems concerned with the changes but they maintain he is stable. They maintain he will one day, once off chemo, overcome these setbacks. I am not so sure.

May 2012

We had another 'stable' MRI last week and Kai continues to tolerate the new protocol. These little blessings are the things I try to keep in the front of my mind. TODAY Kai is doing OK. But it is a hard sell when you look back a year...I am thankful that he is not in the pain from the hydrocephalus he suffered with the first 8 months of his life. I am thankful we now know what is going on. I am thankful we have so many wonderful people supporting us. I am thankful we are doing all we can to help him. But even with all this care and love he is not getting better. It is not enough. A year ago Kai could 'stand' with the help of his dad. Kai would bite a piece of watermelon. Kai could feed himself and drink from a sippy cup. He could sit without falling over. He would hold on when I carried him. He would cry if he were hurt. He could see.

September 2012

It's obvious that Kai has been in pain and it has been getting nothing but worse. Lately his decline has been apparent week to week and now I can see a shift from the day before. He can no longer enjoy most of the things he once did and I fear he is always in pain. The chemo isn't helping. Not just this new protocol but the last one and the one before that. It is failing. His tumor is not responding. We are not giving up on Kai but it is most important to me that he be as comfortable as possible right now, so we are shifting focus.

We took him off chemo. We are now working with PACT to be sure he is comfortable. He was given some morphine and we are going home with methadone, Ativan and other comfort care meds. In a few weeks we will reassess his quality of life and determine whether another course of action is appropriate. For now we

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are thankful that Kai is able to visit with family and friends. We had a last minute birthday party for him that he happily slept through in someone's arms. He is two years old!

October 2012

I was frantic at clinic today. We had a big meeting planned solely focused on end of life care. We were going in to sign a DNR for my baby. We were supposed to be planning his death but my mind has been drifting back to survivorship. I met with the PACT doctor first and explained my desire to seek out a new treatment for Kai. She did not interrupt or interject. She sat through my pitch, listening calmly and carefully, and then said, "If this is what you want for Kai we will all work together to make it happen, but I would also like to remind you of what you told me last week. Do you remember?" Of course I remembered. It is all I think about, every minute of every day. I have always been afraid of not knowing when to say when. I have always been afraid to treat Kai for my sake instead of his… of letting him suffer longer than he should, and last week I made the call. Last week I decided this treatment was only making him more sick. I decided to put Kai first, even if it means I have to watch him slip away. With that one question, the one thing no one else on his team would say to me, I realized I was already doing what is best for Kai. So today I signed a DNR. Today I insisted on hearing the procedure for donating his tumor after he is gone. I announced that I would like him to be cremated and that I am still not yet sure if I would like him to die at home.

November 2012

After 4 days of tests in the PICU it is apparent that Kai's tumor has grown, his shunt is malfunctioning and he is fighting several bacterial and fungal infections. We had a long meeting with his team and we have decided to let him rest, keep him comfortable, and hold him close. No more pokes, no more being woken up every hour for vitals, no more tests. Late last night we unhooked him from most of the wires and traded his hospital crib for a regular bed so he will never lay alone again.

Kai and I slept comfortably most of the night and when we woke I studied him. I stared into his eyes; I squeezed him tight as my silent tears rolled from my face to his. I told him I would do my best to keep him from the pain. As he began to fuss, I hesitated only for a second before calling the nurse for more pain meds. They warned me that as we increase his meds he would wake less and less. I would give anything to stare into those eyes forever but my job now is to make sure those eyes, open or closed, feel no pain.

Kerri's son Kai died in November 2012, at age 2 years.

Virtual Journal Club

By Richard Goldstein MD, FAAP—*Boston, MA*

The Effect of Communication Skills Training for Residents and Nurse Practitioners on Quality of Communication with Patients with Serious Illness: A Randomized Trial, Curtis JR, Back AL, Ford DW, et al, JAMA. 2013;310(21):2271-2281.

Many of us, ever reliant on our abilities to communicate with skill and subtlety in difficult situations, are also involved in teaching communication skills to trainees. The literature related to skills training in palliative care shows that skill building using simulated patient encounters improves the delivery of bad news, responding to emotions, and discussion of the transition to palliative care in recipients. However, no studies have shown whether patients and families find benefit from these measured, enhanced skills.

In *The Effect of Communication Skills Training for Residents and Nurse Practitioners on Quality of Communication with Patients with Serious Illness,* Curtis et al report on a randomized control trial involving 473 internal medicine residents, subspecialty fellows, and nurse practitioner trainees. It compares outcomes of interactions involving trainees receiving an 8 session, simulation based communication skills training, with outcomes of those who received “usual education”. Each session on the intervention arm included a brief didactic overview, including a demonstration role-play by faculty; skills practice using simulation (simulated patients, family, or clinicians); and reflective discussions. Each session addressed a specific topic (building rapport; giving bad news; talking about advance directives; nurse physician conflict; conducting a family conference; do-not resuscitate status and hospice; and talking about dying). As assessed by standardized patient encounters, the course led to improvements in communication skills. I think it is fair to say that this is the kind of curriculum we would all be pleased to teach.

Questionnaires were administered to patients and family members over a period of 10 months following the intervention and compared with others that had been completed 6 months before the intervention. Eligible patients had a median survival of approximately 1 to 2 years (eg, metastatic or stage IV cancer, advanced COPD, stage III or IV heart failure, Child-Pugh class C liver disease), high levels of comorbidities, documentation of a palliative care consultation or a do not resuscitate order, an intensive care unit stay of 72 hours or longer, or age 80 years or older with a hospital stay of 72 hours or longer. Outcomes were assessed using the Quality of Communication questionnaire, an 18 item measure addressing overall and specific aspects of communication; the Quality of End-of Life Care questionnaire, assessing the quality of clinician skill at providing end-of-life care; a depression scale; and a survey of functional status. The evaluations were not for a specific encounter but were directed more globally at all encounters.

The results were surprising. There was no significant association between the training and the assessed quality of communication. There was no significant association between the training and the assessed quality of end-of-life care. The intervention was associated with a significant increase in depressive symptoms. In post-hoc analysis, improved quality of communication was found in patients rating their health status as “poor”(an important subgroup).

How can this be? The authors question the correctness of the patient and family ratings, and suggest that patients and families may require training or prompting to provide an accurate assessment. Frankly, I was surprised at this implication that patients and families were somehow missing something important that would otherwise be captured had professionals filled them out. Really? They also mention the possibility that the intervention may not be effective even though scores with standardized patients are improved. Let’s linger on this point.

Although the findings are “negative”, I think this article offers important things to reflect upon. I don’t think anyone should conclude that this study undercuts the need to teach communication skills and teach them well. As a field, we have a responsibility to train people to approach these issues with seriousness, competence and skill. But this study brings into relief that there may be crucial elements of communication and end of life care beyond the itemizable skills that are typically used to measure the adequacy of such teaching approaches. Maybe the quality that these patients and family members would be looking for resides in other things. These are not intangible things, but may not be what we typically feel comfortable quantifying as skills. I am not merely saying that ‘not everything that counts can be counted’. Rather, if we don’t look for things like presence, authenticity, a willingness and ability to empa-

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thize and share the patient's perspective, or a slowness that stands out from the workday pace of our institutions, we won't find them and understand just how important they are.

Many of us are looked to because we provide a positive white coat curriculum. We walk the talk of relational, human aspects of care, and demonstrate something that supercedes technique. This, after all, is what the experience of palliative care fellowship can foster. I can't help but wonder if emphasizing and measuring this would have made a significant difference.

Please send your comments about these articles to the LISTSERV® at PPCAAP@LISTSERV.AAP.ORG!

Mentorship in Palliative Care

By Tressia Shaw, MD, FAAP—*Phoenix, AZ*

Many of us seek out others with more experience as we look to develop Palliative Care programs around the country or grow our own professional skills. In most instances this is done informally, when we meet someone at a conference or connect over email. Mentorship, however, goes further than just asking a more experienced colleague questions. It includes a relationship that is fostered over time. Various opportunities are available in the field of Palliative Care for more formalized mentorship. Here are some of those opportunities.

General Mentorship

For members of the American Academy of Hospice and Palliative Medicine (AAHPM), a year-long mentoring program is offered to support mentorship pairs in developing their mentorship relationship. The program is designed to support professional mentorship in multiple areas including clinical and research endeavors. Mentors must be identified prior to applying. A stipend is provided to support travel.

http://www.aahpm.org/about/default/yearlongmentorship.html

Educational Mentorship

The Harvard CME course, Palliative Care Education and Practice (PCEP), provides palliative care education and mentorship in skills that include communication, clinical management, and how to teach palliative care skills to others. This program includes two 8-day intensive educational sessions in Boston (usually in November and April). The program includes the use of standardized patient actors, small groups, and other innovative teaching techniques. Between sessions cases are discussed by email and mentorship is provided in an individual project.

http://www.hms.harvard.edu/pallcare/PCEP/PCEP.htm

Program Mentorship

The Center to Advance Palliative Care (CAPC) offers Palliative Care Leadership Centers (PCLC). PCLC offers year long mentorship to programs in any stage of development. The year includes a team site visit to the mentor program (for pediatrics either Minneapolis or Akron) followed by mentoring calls at regular intervals. The idea behind the PCLC is that you don't have to reinvent the wheel when it comes to program development. The curriculum includes program assessment, staffing models, financial sustainability, measurement, marketing, and implementation.

http://www.capc.org/palliative-care-leadership-initiative/overview/curriculum/pclc_peds

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Research

The National Palliative Care Research Center offers career development awards for junior researchers. Although the Center does not identify a mentor for research, it supports the identified mentorship relationship for research through its award. Several other criteria must be met including committing a minimum of 60% time to research and being less than five years post training.

http://www.npcrc.org/content/19/Funding-Opportunities.aspx

While these are all great opportunities, many people may seek to build a mentorship relationship outside of the formal programs available. If you are seeking a mentor, here some ideas on how you can begin:

- Think about how/why a mentor may be helpful for you.
- Identify someone who might serve as your mentor. Often there may already be someone in your field with whom you are acquainted, who could serve in this role.
- Learn a little about your potential mentor and determine if their interests match your needs for mentorship. For example, if you want mentorship in research, look for a mentor who is well experienced in research.
- Have a specific request when you approach a potential mentor. Ask for advice on a specific project or issue.
- Grow the relationship over time with regular contact and follow-up.
- Be respectful of your mentors time and remember to say thanks.

Fellow's Column

By Christopher A. Collura, MD—*Boston, MA*

"No one cares how much you know, until they know how much you care."
- Theodore Roosevelt

Several weeks ago I was stopped in the hospital hallway by a subspecialty attending. Our palliative care team has partnered with him over the course of the year to care for one of his young adult patients with complex chronic lung disease. His strong reputation as a collegial, attentive, and compassionate provider was evident during our work together. He had recently been troubled by his encounters with our shared patient.

The patient was a young woman he had followed in and out of the hospital for years. She had grown more guarded during his visits. At the same time, her relationship with our team deepened. Profound concerns about her pain surfaced as her disease trajectory seemingly worsened. As an insightful provider, the physician noticed this in his patient, and found time away from service to sit with her. He did not describe the plan for the day. The primary team had already reviewed the diagnostic and treatment course. He did not bring up her pain or goals of care. The palliative care team had already addressed these concerns. He simply listened to his patient. He let her dictate the conversation. He eagerly described this visit to me, enthusiastic about how these moments deepened their connection. Beyond the excitement was a reflection of the patient as a person – her hopes as a daughter, her dreams to travel, and her potential to affect real change in the world. His therapeutic relationship had been transformed. He identified the impact it would have on his practice going forward. He shared a new understanding of how palliative care's work in relationship building allows for expansive exploration of symptoms and values.

The therapeutic relationship is the cornerstone of pediatric palliative care. Before we can expect a baby's mother to share her worries about open-heart surgery or a teenager to describe the anxiety of starting a new chemotherapeutic agent, we must have a relationship rooted in trust and understanding. Our rounds do not list subjective and objective history and follow with detached medical assessments. They lead with hopes and fears and follow with empathy and support. We spend our time in consults listening to families and reflecting with patients. Trust, we know, will allow for a better exploration of pain and symptoms, psychosocial concerns, and goals of care.

There is a growing body of evidence that key compo-

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nents of the therapeutic relationship are directly related to patient outcomes. Effective communication, partnership, personal relationships, and interest in the patient's life are all associated with less symptom burden.[1] Population-based studies have demonstrated an impressive relationship between physician empathy and improved clinical outcomes.[2][3] This provider-patient relationship is not unique to palliative care. For most physicians, it likely underscores the reason why they sought a career in medicine.

Many challenges exist in cultivating the provider-patient relationship. Outpatient time constraints barely allow enough time to review test results, let alone perform a sound physical exam and describe the treatment plan. How can physicians expect to discuss family dynamics, spirituality, and hopes for treatment? Inpatient rounds are comprised of more and more players, growing patient censuses, and pressures to produce immediate outcomes in order to reduce length of stays. Exploring anxiety with an adolescent lying in a hospital bed while various providers in yellow gowns peer down is anxiety provoking in itself. Forgive both the physician and the patient if these encounters do not produce an unyielding alliance.

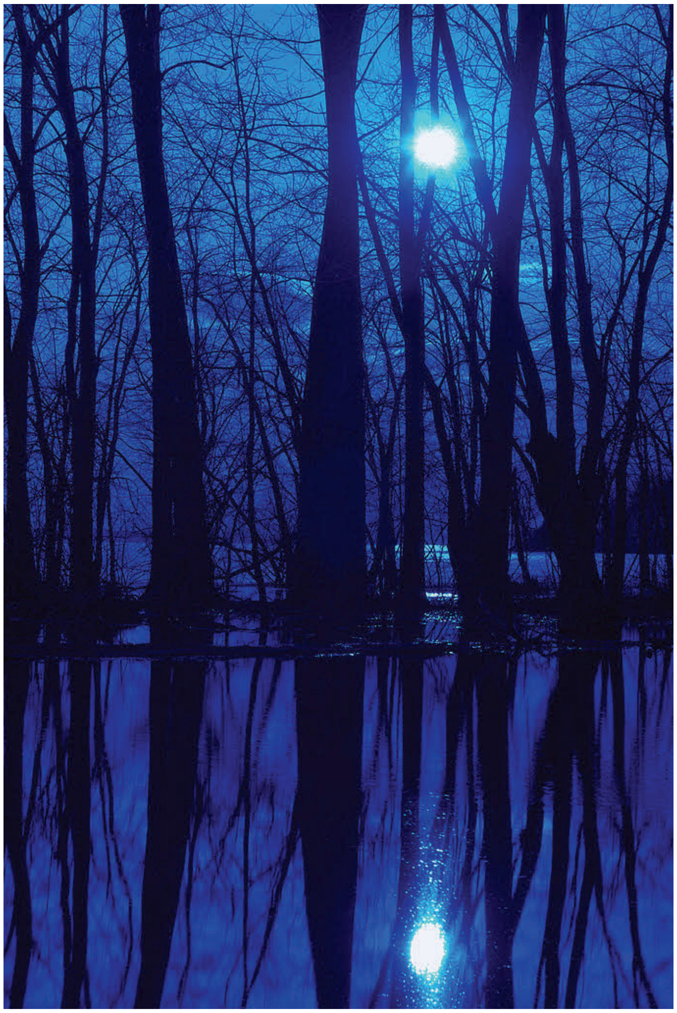
Our specialty must partner with the field of pediatrics beyond patient consultation. Pediatric palliative care should not only provide a therapeutic relationship that may be inhibited by the challenges of an evolving health care system. Education in communication must be expanded during training to facilitate the provider-patient partnership. Work-flow for inpatient teams should be developed to emphasize goals of care as much as medication reconciliation. Value initiatives need to imagine broader outcomes beyond time-laden metrics to drive quality. Medical home coordination for children with special health care needs must be disseminated. Improved health outcomes will follow.

These system-based practices are natural components of palliative care and they all foster a deep-rooted confidence in our patients. Our field should spearhead solutions to overcome the obstacles that impede the therapeutic relationship. It is the foundation of our profession and holds great meaning for the physician and the patient. Palliative care consultation should complement this relationship, but never replace it.

References

1. Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ*. 2001; 323(7318): 908-11.
2. Del Canale S, Louis DZ, Maio V, et al. The Relationship Between Physician Empathy and Disease Complications: An Empirical Study of Primary Care Physicians and Their Diabetic Patients in Parma, Italy. *Acad Med*. 2012;87(9): 1243-49.
3. Hojat M, Louis DZ, Markham FW, et al. Physicians' empathy and clinical outcomes for diabetic patients. *Acad Med*. 2011;86(3):359-64.

We invite contributions from palliative care trainees to be included in future newsletters.



2014 Pediatric Palliative Care Fellowship Programs

(As of as of 2/28/14)

1. **Akron Children's Hospital Pediatric Palliative Medicine Fellowship (2 slots)**
   https://www.akronchildrens.org/cms/pediatric_palliative_care_fellowship/index.html
   Contact: Cathy Kelly-Langen, MD
   ckelly-langen@chmca.org

2. **Children's Healthcare of Atlanta and Emory University School of Medicine (Pediatric Track) http://www.choa.org/Childrens-Hospital-Services/Palliative-Care/Fellowship%20Program**
   Contact: Jeffrey C Klick, MD
   jeffrey.klick@choa.org

3. **Children's Hospital of Philadelphia**
   http://www.chop.edu/service/pediatric-advanced-care-team-pact/home.html
   Contact: Jennifer K. Hwang, MD MHS
   HWANG@email.chop.edu

4. **Cincinnati Children's Hospital**
   Hospice & Palliative Care Fellowship
   www.cincinnatichildrens.org/palliative-fellowship
   Contact: Marybeth Sullivan, fellowship coordinator
   Marybeth.Sullivan@cchmc.org
   Contact: Norb Weidner, MD, Director
   Norbert.Weidner@cchmc.org

5. **Harvard Palliative Care Fellowship (Pediatric Track - 2 slots) http://www.hms.harvard.edu/pallcare/Other/Fellowships.htm**
   Contact: Joanne Wolfe, MD MPH, fellowship director
   joanne_wolfe@dfci.harvard.edu
   Contact: Andrea Boyajian, fellowship coordinator
   aboyajian@partners.org

6. **Jefferson Medical College Program, Nemours/duPont Hospital for Children HPM Fellowship (Pediatric Track), Wilmington, DE**
   http://www.nemours.org/education/gme/fellowships.html
   Contact: Elissa Miller, MD
   elissa.miller@nemours.org

7. **Lurie Children's Hospital and Northwestern Memorial Hospital (NMH), Chicago, IL (Pediatric Track)**
   Contact: Joshua Hauser, MD
   j-hauser@md.northwestern.edu

8. **University of Florida Jacksonville (Pediatric Track)**
   Contact: Kelly Komatz, MD
   Kelly.komatz@jax.ufl.edu

9. **University of Michigan Ann Arbor**
   Palliative Care Fellowship (Pediatric Track)
   http://www.med.umich.edu/geriatrics/edu/hospice.htm
   Note: Applicants require funding from home institution
   Contact: Terry Murphy
   tmurph@med.umich.edu

10. **University of Minnesota: Hospice and Palliative Medicine Fellowship (Pediatric Track)**
    Children's Hospitals and Clinics of Minnesota
    http://www.fm.umn.edu/education/fellowships/hpm/home.html
    Contact: Kris Catrine, MD, pediatric fellowship director
    Kris.Catrine@childrensMN.org

11. **University of Tennessee Palliative Care Fellowship (Pediatric Track - 2 slots)**
    Contact: Le Bonheur Children's Hospital site director
    Melody Cunningham, MD
    mcunni16@uthsc.edu
    Contact: St Jude Children's Research Hospital site director
    Justin Baker, MD
    justin.baker@stjude.org
    Contact: Catina Pricel, fellowship coordinator
    catina.price@mlh.org

12. **The University of Texas Medical School at Houston (Pediatric Track)**
    Contact: John Halphen, MD
    John.M.Halphen@uth.tmc.edu

13. **University of Washington Palliative Medicine Fellowship (Pediatric Track) http://depts.washington.edu/pallmed/**
    Contact:: Ross Hays, MD
    ross.hays@seattlechildrens.org
    Contact:: Fellowship Coordinator, Betsy Zickler
    eazickle@u.washington.edu

If you know of additional training programs, please let us know!

Program Profile

Name of Program: Notre Dame Pedi Pals Program

Location: Notre Dame Healthcare Center
Worcester, MA

Contact Information/Credentials:
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Website: www.notredamehealthcare.org

Service Delivery Model: The Notre Dame Pedi Pals Program is one of ten Pediatric Palliative Care Programs in the state of Massachusetts, funded annually by the Massachusetts State Legislature. It was first funded in 2006 as part of then Governor Mitt Romney's "An Act Providing Access to Affordable, Quality, and Accountable Care," which established The Massachusetts Pediatric Palliative Care Program. The program is administered by the Massachusetts Department of Public Health, Division for Children and Youth with Special Health Needs. The goal of the Pediatric Palliative Care Network is to improve the quality of life for families caring for children with life-limiting illness and to provide comprehensive community-based pediatric palliative care services.

Notre Dame Pedi Pals serves the unmet physical, emotional, social and spiritual needs of children in Massachusetts with life-limiting illnesses. Services are provided at no cost to children 18 years old or younger who have been diagnosed with a life-limiting illness, even when a cure remains a possibility. While many patients are receiving services such as block nursing, early intervention, and visiting nurses, Notre Dame Pedi Pals intends to bridge the gap in services by including services otherwise not offered or covered by insurance. These services include in-home support, case management, spiritual care, social services, counseling, music therapy, massage therapy, child life services and volunteer support. Support is also offered to those families in need of Perinatal Palliative Care. An important aspect of palliative care is bereavement for the entire family unit. Notre Dame Pedi Pals offers a bereavement model which includes education, guidance and support from a team specializing in the loss of a child. Education is provided to families as to what to expect, stages of grief, and misconceptions of the grieving process. Guidance offers strategies to cope with the adjustment, coping mechanisms, and clinical support. Support includes community support groups, grief counselors, and community organizations dealing with loss especially loss of a child.

Annual Average # of Patients Served: The Notre Dame Pedi Pals Program has provided care to over 100 children including patients and their siblings since July 2012.

Staffing of Team: With a unique emphasis on family centered-care, the team is comprised of various palliative care disciplines specializing in pediatrics. An interdisciplinary team approach is utilized and the team includes a social worker, nurse, music therapist, massage therapists, child life specialist, chaplain, and volunteers under professional supervision.

Funding source(s): Massachusetts legislature as a line item in the state budget, private fund-raising, grants

Research: Notre Dame Pedi Pals Program is not actively participating in any research studies.

Memorable challenge: Most models of pediatric palliative care are based on a medical model of care; the Notre Dame Pedi Pals Program is a psychosocial based program. The emphasis to provide family-centered care instead of care solely to the patient has been both a challenge and a great success. Unique features of this community based pediatric palliative care program include a strong emphasis on complementary therapies such as music therapy and massage therapy. The social worker, the child life specialist and members of the team of complementary therapies work as key disciplines, along with the nurse's guidance, to develop a plan of care based on the families' psychosocial needs. With so much importance placed on the patients' medical needs, professionals can easily overlook the emotional toll the illness can take on the entire family at home. While acknowledging, supporting and understanding the complex medical diagnoses of our patients, our multidisciplinary team works to address the impact on the psychosocial needs of the family unit. Collaborative partnerships and communication among all members of the patient's healthcare team improves

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coordination of care. We continue to work towards integrating various therapies to improve the patient's quality of life. Therapies such as hippo therapy, pet therapy, medical clown therapy and aqua therapy are all vital in the support of the patient's illness and emotional well-being.

Memorable success: The Notre Dame Pedi Pals Program began in July 2012. Since then it has expanded services and shown a rapid increase in census, as the team has evolved. The team has come to realize that although the diagnoses cannot be changed or their paths reversed, the journey can be made a little less isolated and a bit easier. As stated by the music therapist, "It amazes me all the time that I am allowed to be in the same space as people who are going through a difficult time and that I'm welcomed to be a part of the experience. It also amazes me that by me simply coming in to offer my music therapy I can help these families in a huge way. To be able to help a family even in a small way leaves me with such great satisfaction that I find I am craving the work and looking forward to each day where I can come in to a family's home and do what I do."

Upcoming Meetings

March 12-15, 2014 in San Diego, CA
American Academy of Hospice and Palliative Medicine (AAHPM) Annual Assembly

March 15-16, 2014 in San Diego, CA
EPEC-Pediatrics Master Facilitator Course

April 3-5, 2014 in Boston, MA
Palliative Care for Hospitalists and Intensivists

April 10-11, 2014 in Dallas, TX
ELNEC-Pediatric Palliative Care Train-the-Trainer Course

April 30-May 6, 2014 in Boston, MA
Program in Palliative Care and Education Practice (PCEP) 2013-2014

June 7-13, 2014 in Minneapolis, MN
7th Annual Pediatric Pain Master Course

June 12–13, 2014 in Boston, MA
The Art & Science of Palliative Nursing 2014

July 29-30, 2014 in Chicago, IL
ELNEC-Pediatric Palliative Care Train-the-Trainer Course

October 11-14, 2014 in San Diego, CA
AAP National Conference and Exhibition (NCE)

October 25-29, 2014 in Nashville, TN
NHPCO Clinical Team Conference and Pediatric Intensive

November 4-11, 2014 and May 6-12, 2015 in Boston, MA
Palliative Care Education and Practice

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Submissions:
All section members are invited to send articles or suggestions to Rick Goldstein, the newsletter editor.

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