ChiPPS Pediatric Palliative Care Newsletter
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Edited by Charles A. Corr, PhD, Christy Torkildson, RN, PHN, PhDc, and Maureen Horgan, LICSW

Issue Topic:
Children Are Not Little Adults: Some Differences in Providing Palliative Care

Welcome to the twenty-eighth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving differences in providing palliative care to children and their families by contrast with services to adults. Our goal in this issue is to promote reflection on some of the distinctive features of providing palliative and hospice care to children and to encourage a dialogue with individuals who are more familiar with adult palliative care.

This newsletter is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-newsletter Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-newsletter Workgroup, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at torkc@sbcglobal.net or Maureen at Maureen.Horgan@providence.org.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Children Are Not Little Adults: Some Differences in Providing Palliative Care

Summer Camp
Scott Newport
A bereaved father who has been a consistent and poignant parent voice in the ChiPPS e-newsletter shares a story about the power of ritual for connecting with children in families who have a child with serious illness or who have experienced the death of a child.

Virginia's Charter: For Children and Young People with Life-Limiting Conditions and Their Families
Virginia Barstow
A mother, whose son Lawrence died in 2005, shares fourteen suggestions about how to support children and young people facing life-threatening conditions. This article is reprinted by permission from Together for Short Lives (formerly ACT).

One Size Does Not Fit All: Differences Between Adult and Pediatric Palliative Care
Suzanne Toce, MD
Attention to the unique needs of seriously-ill children will help our medical communities assure that all children receive expert palliative care. Dr. Toce provides a general overview of the special needs of children living with serious illness.

Life is a Beach
Rebecca Brown, BM, MDiv
Chaplain Rebecca Brown uses metaphor to provide a framework for describing the lives of teenagers living with serious illness.

Caring for Pediatric Hospice Patients in an After-Hours and Weekend Setting
Elizabeth Comstock, RN, BSN, CHPN, and Jen Jacobson, RN, BSN
Two visiting nurses at Providence Hospice of Seattle provide pointers for hospice nurses who primarily care for adults and only infrequently visit with pediatric palliative care and hospice patients at home. Their primary training and focus has been with adult population. With training and encouragement, they provide compassionate and exceptional care knowing that all persons regardless of their age should have access to hospice and palliative care at home.

POLST for Pediatrics Unveiled
Leslie Adams, MSW, and Paola Bruni
Leslie Adams, consultant with Children’s Hospice and Palliative Care Coalition, and her co-author provide a brief overview about how to begin conversations with parents and children to better communicate and document their wishes for end-of-life care on the POLST form. This article is reprinted by permission from HOPE magazine.

Children Are Not Little Adults When It Comes to Pain Management
Kelly Komatz, MD, MPH, FAAP, FAAHPM
“If it hurts in an adult than it hurts in a child.” Pediatric Palliative Care Physician Kelly Komatz provides an overview of the unique physiologic features of pain experienced in infants and children along with a brief review of pediatric tools used for evaluation of pain.
Child Life Specialists: Core Clinical Team Members in Pediatric Palliative Care  
Rebecca Simonitsch, MA, CCLS

Child life specialists work to normalize the environment for chronically and acutely ill children, focus on children’s strengths, optimize developmental growth, offer opportunities to gain a sense of mastery, and promote self-expression. Rebecca Simonitsch provides an overview of the role of child life clinicians, an outline of activities child life participates in, and a case review. Perhaps your team will consider hiring a child life specialist to enhance the life of your team and the families you support.

Stewards of Trauma  
Robyn Callahan, MSW, LSWAIC, and Samantha Wipperman

Caring for dying children and adults is challenging and sometimes traumatic. The authors of this article acknowledge that professionals in caring professions experience trauma and need to reflect upon and digest their experiences to provide ongoing healing care. The article provides practical approaches to caring for one’s own being while caring for others. This article is reprinted by permission from NASW InterSections in Practice, Issue NO. 5, 2011.

Transition to Adult Health Care for Youth with Special Health Care Needs Bibliography

This bibliography is reprinted by permission from the Institute for Patient- and Family-Centered Care.

Reader’s Corner  
Suzanne Toce, MD

This contribution describes a journal article that reviews updated research on end-of-life care sedation (EOLC-S) for children and aspects surrounding this issue.

Items of Interest

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

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

Scott Newport
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I guess Penni must have picked up on some wisdom from other camp moms when she announced her idea of hiding a little love note between Noah’s underwear and his new swim trunks. Noah was nine years old and this would be his first, week-long camp experience. Not wanting to be out-parented, I also put an envelope in Noah’s suitcase. I just jammed my envelope toward the bottom.

All week I worried if Noah would be homesick and waited for the phone to ring. Friday was here before I knew it. Noah walked into the house and you could tell he had a good time. Story after story broke from his lips and then I interrupted. “Did you open the envelope?”

“Yea dad,” he replied.

Wondering, I asked, “Well, what did you think?”

“I held it every night before I went to sleep.”

This past week Linda the social worker from Walk With Me called. She asked if I could stop by and see a family at our local hospital. You see, Walk With Me is a pediatric hospice and palliative program and I am a graduate. Our son, Evan, died a couple of years back; I now have a strong passion to help other families on their journey.

Before I went to see them I wondered what I would say. While working in my wood shop I remembered the story about Noah and the envelope. I soon found myself taking some old Redwood I reclaimed from a deck on Lake Michigan and cutting it up into small pieces about the size of a harmonica. I then split each of those pieces in half creating a mirror image of the other. In woodworking we call that, “book matched,” a technique often used when making fine violins or the interiors of Rolls Royce’s.

So when Noah opened his envelope there was no note but a small piece of Redwood with all of the names of the other members of our family engraved there: mom, dad, Chelsea, and Evan. On the mirrored piece I kept, I had the name Noah written on it.

You see, I hoped when Noah opened his note from me he would be reminded of his family. My plan worked. While he was holding onto his each night, I was holding on to mine and then laying it on my bed stand while I slept.

During my visit with the family I told them about the wood and gave them a sample asking if they had any ideas how this could help families especially if a parent had to leave their child. While the dad and I talked the mom was standing at the nurses’ work desk. Within about fifteen minutes she had asked for ribbon, a pair of scissors, and some markers. Luckily I had come prepared.
When she was done she showed me. When she put both pieces together like pages from a book her creation was an assembled heart. Each stick had its own inscription. One side said, “Love ties us together,” and the other “Even when we’re apart.”

I just loved what she had done. I told her to keep it and to send me a picture. I’m hoping this may be a new way to help families who are on the journey of having a child with a life-limiting disease.

And if you’re wondering, Evan had a piece of Redwood too with all our family names on it. My half is still on my bed stand and Evan’s was buried, neatly nestled in his folded hands.
VIRGINIA’S CHARTER:
FOR CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS
AND THEIR FAMILIES

Virginia Barstow

In the Spring of 2004 my son Lawrence, who was six at the time, developed problems with his hearing. These problems got worse over the next few months and in October 2004 Lawrence was diagnosed as having ALD – a rare genetic degenerative condition made famous some years ago by a film called "Lorenzo’s Oil." The condition took its hold rapidly. In December 2004 Lawrence lost the ability to walk, literally overnight. Over the next few months Lawrence lost his speech, the ability to move, and had to be tube fed. Lawrence died in July 2005, just nine months after the diagnosis, at the age of eight.

I was asked to speak at a recent ACT conference in my capacity as a parent, and decided to focus on what would have made both Lawrence’s and our experiences as parents at this terrible time easier. I came up with the following fourteen suggestions:

1. Better training for professionals on breaking bad news to parents.
2. For rare conditions – an expert should be available to give information and advice throughout the progress of the condition.
3. More support from the GP surgery – a single GP should be appointed in charge of the case and to keep abreast of developments. Ideally someone with a palliative care background.
4. The appointment of a “child’s champion” for every child and his or her family - to look after the interests of the child and to co-ordinate all involved in care.
5. The ability to make decisions and adapt quickly to changing circumstances and the ability to bypass bureaucracy when necessary. For example, ensuring the child has specialist equipment or housing adaptations are sorted when they are needed.
6. More funding should be made available to help with the promotion of specialist and support groups working across children’s palliative care, especially those small groups that provide help and information for rare conditions.
7. Recognition of qualities of “special children” - they have much to teach us.
8. Acknowledgement that the parent does sometimes know best, and professionals should do more to listen to what parents say.
9. Professionals should be more willing to seek advice from other professionals who have more experience about a specific condition or issue.
10. Pain relief must be given a priority.
11. Emphasis should be on a peaceful death rather than prolonging life. Good quality palliative care when the patient is alive and a peaceful death are key. Palliative care workers deserve recognition for the huge difference they can make to the quality of a patient’s last phase of life.
12. Parents should be made aware of options for death at home and a more “DIY” approach to funeral/cremation, rather than be railroaded into using the services of a funeral director.

13. The child’s champion should stay in touch with the parents, sibling, and family after the child has died, to provide ongoing support as they come to terms with their loss.

14. Parents should be encouraged to do something positive in memory of their child.

These suggestions are based purely on our own personal experiences and I’m sure many readers will have other suggestions to add to this list. If you would like to add anything, or to make any points about my list, please get in touch with me via Myra at ACT – myra@act.org.uk

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Intellectually, we understand that children are different than adults. But when it comes to children with life-limiting conditions, it may be appealing to try to apply the same strategies that seem to work well in adults. But ONE SIZE DOES NOT FIT ALL.

Compared to adults:

- Fewer children die; around 50,000 per year. Perhaps the scarcity of skilled pediatric palliative care providers can be explained by the small numbers of children receiving palliative care. Expert pediatric palliative care may be at tertiary children's centers far from the child's home.
- Children die of a broad range of conditions, some of them very rare.
- Heritable childhood conditions may affect multiple family members, putting a huge physical, psychosocial, and spiritual burden on the caregivers.
- Childhood conditions have a variable time course, frequently different from adults.
- Children with life-limiting conditions frequently live longer, many for >1 year beyond initiating palliative care. Previously diseases such as cystic fibrosis, Duchene muscular dystrophy, and complex congenital heart disease that were fatal in childhood now have improved management. There are limited medical and palliative care services for young adults with these conditions.
- The uncertain prognosis of childhood conditions may be a barrier to appropriate institution of pediatric palliative care. Of course, as Betty Davies has written, “an uncertain prognosis should be a signal to initiate, rather than delay, palliative care.” In addition, as hospice funding generally is based on an expected life span of <6 months, lack of certainty of life span may be a barrier to utilizing the hospice benefit.
- Children are continuing to develop physically, cognitively, psychosocially, and spiritually throughout their illness/condition. Their concept of death goes through similar changes in understanding. Transitioning into the next developmental stage may be delayed because of the disease/condition. Conversely, children may have an understanding of their condition and prognosis that is greater than that expected by their age or developmental stage. Play and education are important to them.
• A child is not a legal decision maker. Parents provide informed permission acting in the child’s best interest. Children should, however, be involved in decision making to the extent of their capacity.

• Care of the child is in the context of the entire family and “extended family.” Support for the family, including siblings and grandparents, is extremely important. The extended family may include school, faith organizations, and friends.

• Because of limited community resources, the child is less likely to die in her/his preferred site – home. More children die in the hospital, frequently in an intensive care setting.

• Funding for pediatric palliative care is inadequate. Many children are receiving expensive life-prolonging and palliative care concurrently. New federal regulations mandate funding for concurrent care for Medicaid patients. That leaves many children whose needed services are unfunded. No one makes money providing pediatric palliative care.

• There is less evidence underpinning pediatric palliative care assessment, management, practice, and outcome measures.

• Children are not expected to die young and predecease their parents. Reluctance to accept that children die affects not only parents but also health care providers who may feel that they have failed if the child dies.

• Major barriers to instituting pediatric palliative/hospice care include parental reluctance to accept a terminal prognosis, discrepancies of goals between the parents and providers, and misperception that hospice/palliative care means failure or giving up hope.

All palliative/hospice care should be individualized to the patient, their support people, and the community resources. Children are special and have needs that are different from but overlap with those of adults. Attention to these unique needs will help ensure that each child receives expert palliative care concurrent with life-prolonging treatment or as the primary goal of care.

Do you want to learn more? Here are some interesting resources:


LIFE IS A BEACH

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Picture life, like time spent on the sandy shore line of a beach. Our lifetime is spent building a sand castle. We are born with our backs to the ocean, knowing all the while it is there. We hear the sounds and once in a while a wave actually comes up and chills our feet with a reminder, but we know the tide cycle and it is not expected in until a person is in their late 70s or even 80s. At least that is the word on the beach. Most of us are taught much of what we know about the beach by our parents, our religions, and our culture. These three influences tell us how to deal with sunburn, how to make a successful sand castle, and indeed define for us what a successful sand castle is. They teach us how to withstand the bullies on the beach and the rain, and still have time to enjoy the whole process. But they cannot control the ocean.

As children we spend most of our time learning from our parents the rules of the beach and how to make sand drizzle, motes, and sturdy castle walls. Somewhere around the age of 15 or 16 (if not earlier) we don’t want the instruction and supervision, so we send our parents back to concentrate on their own castles. We want to try this skill ourselves. And yes we make mistakes, and yes, our castle may look completely different from the design plans we received from our parents, but that is half the fun! So we build and drizzle and design our sand castle, and it feels liberating to try things without our parents always knowing and correcting.

Once in a while, we hear about a rogue wave that has taken away a beach neighbor unseasonably early. Their tide came off schedule. But that happens sometimes. Maybe the tide even takes away someone close to us. We get frightened, and think about looking over our shoulders at the ocean, wondering if this tide schedule can be trusted, but after all, we are young, and should have lots of time. Although none of us knows the exact time, we feel comfortable living with that uncertainty because we are young.

Life for the Young Person with Cystic Fibrosis

From the time he can remember he is in and out of hospitals and told he is sick. Mom and Dad are very worried about the ocean. At some point he is told (or figures out?) that his wave will come in sooner than others on the beach, that he doesn’t have much time. While very young he makes his sand castle with mom and dad and tries to ignore the ocean. The rogue waves that reach his toes, those random scares that happen, are just part of life for him. But as a teenager he wants to do what other teens are doing with their sand castles, but Mom and Dad are there to caution. Sometime during his adolescence he turns himself around to face the waves he cannot control, stops, and decides to live with it. Everyone else on the beach has their back to the ocean—so he feels alone and different, but he watches and waits and builds his sand castle with the best fortifications he can against the wave that he knows will come. He prefers to build with the ocean in his view. Some CF-ers choose to have it in their ears only, building their castle with abandon and a flick-off to fate.

Life for the Sickle Cell Teen

Every time she starts to build something cool, a little touch of water comes and melts it away—not the whole castle, but enough of it to keep from ever making progress. Nothing can stay put with the waves dribbling in so often. Why bother? The water just keeps interrupting the process. Mom and Dad encourage her, but they don't know what it feels like. Some doctors think she is exaggerating about the water's impact. Some school teachers say she’s not trying hard enough, or that she is lazy. Why can't she keep up with the others? She should have half her castle built by her age. Instead she is making excuses about water and pain crises. She
needs to keep up, but she can't. As a teenager she starts to realize the things she may not ever have—a family, a job, a college education. Is it really worth trying so hard when the water keeps coming and taking it away? Starting over… always starting over. Someday there will be a wave that will take the whole castle. This she knows.

**Life for the Teen Living with Cancer**

Unlike the Cf-er or Sickle Cell teen, everything has been going just fine for this teenager. He's got big plans for his castle, and he is well on his way. High school is framed to set him up for a successful future. Relationships with girls are getting interesting and he is feeling like a young adult. He drives a car now, buys his own clothes and is starting to figure out his personal castle design. And then comes this wave—a rogue wave, big, and loud, and sudden—crashing down on his castle—turning it to sludge. Up until this point he'd hardly even been aware of the ocean behind him. He turns around now though and looks it right in the face. Cancer. Old people get that, don't they? But this rogue wave has made him very aware of the large glistening ocean that is both unpredictable and a little frightening. He looks down the beach at all his friends building castles with their backs to the ocean. He will never feel quite the same about the castle he will rebuild, nor will he ever forget that the ocean is there, because he lives facing it—not so much in fear, but with understanding, and a greater appreciation for the life and time he has been given on the beach.

**Notes:**

This essay is inspired by the response given by one of our cancer survivors, when we asked how best to support a girl in our care who had a cancer relapse and was now terminal. He said, "Just help her build her sand castle" … Wise words from a 17-year-old teenager.

There are other chronic and life-limiting illnesses that affect teenagers like heart, liver, and renal failure, lupus, epilepsy, and others. Our primary recurrent populations have been the above three and so this essay is written to reflect their situation.
CARING FOR PEDIATRIC HOSPICE PATIENTS
IN AN AFTER-HOURS AND WEEKEND SETTING

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Most hospice nurses, in our experience at our large urban hospice, feel about pediatric hospice nursing as the general population of nurses seem to feel about hospice nursing. That is to say, we could do many things, but this wouldn’t be one of them. We think to ourselves how grateful we are to those nurses who feel attracted to the work. Jen and I are adult hospice nurses doing triage visits during evenings and nights in a hospice large enough to have its own pediatric program. For a long time, the pediatric nurses were doing their own after-hours on-call, making visits as needed. However, as their caseload grew they made the reasonable choice to give up making their own after-hours visits and turned that responsibility over to the Triage Department. This is a brief outline as to how we, as adult hospice nurses, have learned to cope with making pediatric visits.

Jen: I have been a nurse since 2000 and have been privileged enough to have had a wide and varied career. I have worked in large teaching hospitals in almost every major city up and down the west coast. I have cared for patients with cancer, heart disease, and those awaiting organ transplantation, as well as emergency medicine. I have been consulted as a clinical expert while working with attorneys on medical malpractice lawsuits and wrongful death cases. I have even owned my own Nurse Consulting business. However, after coming to hospice care, I was shocked at how entirely unprepared I felt walking into my first pediatric hospice patient's home. It was as if my entire career came suddenly crashing down around me—my prior experience seemed null and void.

Hospice called to me during a time when I had become more introspective about my own life. The adrenaline of acute care no longer appealed to me as it once had. The endless medical record review that was a part of working with attorneys left me longing for real patient contact. It was about this time that I got the call from my mother that my grandfather was dying. I left Los Angeles and moved home to Seattle. I was honored to have had the opportunity to care for my grandfather as he died on hospice, and this experience made it clear to me that no other kind of nursing would ever feel right again.

Elizabeth: Three years after my father died, I decided to leave a long career in Public Health and do hospice nursing. My father had been on hospice for five months and the experience was transformative. I felt that hospice care was the most radical area of health care that I had ever experienced. How amazing that such subtle support for us as a family and for my father could be so powerful. In choosing to work in hospice, I wanted to help families the way I felt mine had been helped; giving them the support and skills to face the end of life.

I felt confident for two reasons: I knew hospice care could transform the experience of end of life; and I knew I wouldn't personally be working with terminally ill children. To me, this second issue was critical. Part of what attracted me to hospice was that it was an alternative to our modern cultural denial of death. But honestly, when it comes to dying children, I am part of that denial. I don’t want children to die, I want something, anything, to be done to help them live.

Jen: Truthfully, the expertise that is required to care for the dying child is not inherent in the skills base of most hospice workers. After all, we care for a predominantly elderly population. This is as it should be, we
think. Death should come only after a long, well-lived life, surrounded by our loved ones, in the comfort of our own home and with our dignity intact. That scenario means “dying well” in our eyes.

Some of us come into this field from the acute care setting, or after one of our loved ones falls ill and we are exposed to hospice nursing for the first time. Some of us come from a community health nursing model, and long for the connectedness and closure that caring for the dying and their families can bring. However, either way, most of us have very limited clinical exposure to pediatrics.

Certainly our society, our schools, and universities—even our faith communities—do not readily acknowledge terminal illness in children. Before beginning my journey as a hospice nurse, I could not fathom it. Usually those of us who work in hospice have thought of our own mortality, but few of us have contemplated, even for a moment, the gut-wrenching loss of a child. As a mother of two, and a step-mother to three more, my single greatest nightmare is being in the place that these families are in.

Elizabeth: In making pediatric visits, I was surprised at the similarities between the parents of young children and the parents of adult children. Whether someone is dying at age one or one-hundred, any related family member may be resigned or stubbornly defiant; quiet or very loud; in a panic or in a state of grace; or, as is usually the case, a little mix of everything. Loss is so difficult, it feels so unfair, and ultimately it isn’t any different for a teenager to lose her father than a father to lose his teenager. It can leave us as hospice nurses speechless, sitting quietly, attempting to be a witness.

What has been so meaningful for me, and has empowered me to face families of young children, is the wonderful support and responsiveness of those who work in pediatrics. The pediatric team at our hospice has been ridiculously kind, encouraging and appreciative of our efforts. They’ve actually inspired me to remember to treat all of my coworkers this way! And working with the pediatric physicians after hours has been a stunning experience. The physicians want to be actively involved and are immensely understanding, not only of where the families are coming from, but also of us, as after-hours nurses.

I still take slow, deep breaths before pediatric visits. And not surprisingly, that is also Jen’s first piece of advice to the adult hospice nurse. So take a deep breath and let it out, because you are not alone.

Jen: Well, let us set panic aside and keep things simple. We must develop a plan of assessment and useful tools to have on-hand during pediatric visits. The key is to keep visits focused and to remember a few core concepts.

Your nursing toolkit should include the following:

1. **Breath:** Yes, you – take a deep breath. Nursing and caring for the dying is far more an art than a science. But you must calm your own emotion, and make the decision not to put yourself in the shoes of the parents. You must be the focused calm in this parent’s stormy night. You know the still, quiet, gut reaction that is your nursing instinct will signal when something is wrong. It works with the pediatric person as well. But it won’t if you are too busy hyperventilating into a paper bag.

2. **Remember your first line assessment tool.:** No, it’s not your stethoscope, thermometer, or even your eyes and ears. It is this child’s family. The family has been the vigilant caretaker, dedicated assessor, comforter, advocate, and supporter of their sweet child. They have the medical record memorized, they are the most excellent of all historians and they are your single best assessment tool. If they are calling to say there is a new symptom, unrecognized, never experienced before, and unresponsive to the treatment on hand – listen and believe.
3. **You are part of a team, reach out for help.** Have you ever tried getting a hold of the PCP or even the on-call MD at 2am on a Saturday night for your geriatric hospice patient? You may have had no luck at all. You were probably left feeling like you had to keep the patient “patched-up” until daylight dawned and the MD was more available. Well, this is not the case with pediatrics MDs. Here is a group of physicians and nurse practitioners who WANT to be called and informed of changes, lend a hand, and troubleshoot the problem with you – even at 2am. In this setting, know that all you need to do is listen, observe, assess, and report the problem. Let the team help you find the solution.

4. **It is impossible to overreact.** Have you ever heard your peers say that “there is no such thing as an emergency in hospice care?” Well, that statement is true *sometimes*. That wonderful scenario I outlined on the first page, where we have “grandma” who has lived a long wonderful life and is dying at home, surrounded by her amazing family, pain-free, resting with her Pomeranian named Trixie - will probably not have any emergencies. It does not work this way with pediatrics. Pediatric hospice patients and their families face each new morning with the promise that their lives will be short-lived. They may not reach the milestones or traditional expectations set up by society to ‘accomplish’ a life well lived. Each day is delicate and precious, and demands the fundamental right to live as long as they are able - with dignity, support, and good symptom management. If you feel that your patient is unstable, potentially unstable, needs an assessment that cannot be completed in the home, has poorly managed symptoms despite your best efforts – move to a higher level of care. Call your Children’s Urgent Care or Emergency Department and inform them that you are sending your patient. Again, go with your gut. This reaction is not overreaction when it comes from sound clinical judgment and good critical thinking.

This is your survival 101 guide to after-hours pediatric hospice visits. This is, of course, a pared-down and simplified format. It is meant to help clarify the top four things to keep in mind during potentially emotional visits such as these. These tools can help you complete an unexpected visit, for an unplanned event, in a very ill child’s life.

You do have the tools and intuition to do it. And each time you do, and you not only bring peace to the family, but you feel a little less panicked, and an easier breath the next time you get a call for that precious pediatric patient.
POLST FOR PEDIATRICS UNVEILED

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Paola Bruni

Is it always best to perform CPR when a little heart has stopped breathing?

Does there come a time when comfort supersedes potentially life-prolonging measures?

Who decides what type of medical treatment is best for a child?

It’s a joint decision between parents and physicians, says Leslie Adams, lead investigator and coordinator for the Physician Orders for Life-Sustaining Treatment (POLST) for Pediatrics curriculum. “Parents have an intimate knowledge of their child while doctors provide medical expertise. Both perspectives are equally important.”

Children’s Hospice and Palliative Care Coalition and the Coalition for Compassionate Care of California designed a curriculum to train pediatric care teams to have meaningful end-of-life discussions with parents. The curriculum, slated for release this year, guides clinicians through the process of using a POLST form to document end-of-life healthcare decisions. According to Adams, the POLST conversation is uniquely challenging when a patient is a child. “No parent wants to discuss a child’s potential death,” she says. “But parents need to understand the context and consequences of every decision they face, or they will spend the rest of their lives wondering if they made the right choice.”

Core essentials covered in the POLST for Pediatrics curriculum:

Get to know the child and family before considering a discussion about the POLST.
Engage in conversation. “Tell me about your child. Who is she when she is not in this hospital bed? What is important for her quality of life? What factors contribute to your medical decision-making?” A mother who says, “God has placed me on this earth to keep my child alive as long as possible” is going to make a different decision than a parent who says, “I have watched her suffer and I think she has suffered enough.”

Explain the short- and long-term consequences of each treatment option in plain language.
Medical jargon may make sense to someone with a clinical background, but to most people it’s a foreign language requiring translation. Adams recalls a physician who sought approval from his patient’s parents to connect their son to a ventilator. The family agreed, anticipating that the machine would keep their son alive. However, they were not told that their son was unlikely to breathe unassisted again; that he would need to be transferred to the intensive care unit which he hated; and that once the tube was inserted into his windpipe, he would be unable to speak. He also would be sedated to minimize the discomfort created by the tube. Had the parents known the full consequences of their choice, they may have taken time to savor their son’s voice. They may have expressed sentiments and feelings before their son was placed on the ventilator and rendered unaware of their presence. Or perhaps, an altogether different choice would have been made.

Make recommendations based on expertise.
A physician’s counsel should clarify which life-sustaining treatments might be beneficial and which might not. Doctor recommendations are important information as parents consider medical decisions. No parent
wants to feel alone in making the decision to halt aggressive intervention. As one mother said, “I cannot have a hand in my child’s death.” A doctor who openly shares clinical judgment with the family also shoulders part of the emotional burden. POLST conversations are among the most sensitive a family and clinician will engage in, says Adams. The POLST for Pediatrics curriculum will help. For more information, go to www.childrenshospice.org.

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CHILDREN ARE NOT LITTLE ADULTS
WHEN IT COMES TO PAIN MANAGEMENT

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Perhaps the one overwhelming obstacle that palliative providers face when caring for infants and children is how to assess and manage their pain related to their chronic condition and/or an acute exacerbation of pain. This feeling of uneasiness validates the health care professional in recognizing that there are unique features in treating a child’s pain and it goes beyond “just using a smaller dose than we would in an adult patient.” This article will review briefly the unique physiologic features of the pain experience in infants and children, while also briefly reviewing the tools used to evaluate pain in infants and children and touching on some non-pharmacologic methods to help ease an infant’s or child’s distress due to pain.

It was not too long ago when medical professionals believed that infants were “incapable” of feeling pain because their nervous systems were not yet fully developed. Beyond the inability to feel pain, professionals further believed that infants and children would NOT remember any painful experiences and thus at best professionals used only acetaminophen to control for any pain during a procedure. Thankfully, times have changed and the medical field has made large strides in controlling for pain in infants and children. Appropriate pain management is now considered an ethical mandate in both adults and children.

Many studies have been published where the authors demonstrate the pain response in infants, including premature infants. Because of underdeveloped nervous systems in infants, they are more likely to have an exaggerated response to painful stimuli. Beyond this fact, as infants continue to undergo noxious or painful stimuli during the development of their nervous systems, they are at increased risk for creating a long-term increased sensitivity to painful stimuli (Schecter, Berde, & Yaster, 2003, Chapter 4).

The spinal reflex response to mechanical skin stimulation is exaggerated in young infants when compared to those in adults. In infants, there appears to be a lack of descending inhibition, or the ability to release the body’s own endogenous analgesia, as well as the inability to “reason away” the painful stimuli with higher cortical function as you would expect in an adult patient or perhaps a child.

So, then, shouldn’t a child be able to “reason” away the pain from a noxious stimuli or procedure. The studies again demonstrate that uncontrolled pain during medical procedures will alter the child’s acute pain thresholds. There are many factors that contribute to a child’s interpretation of a painful stimulus including: age, cognitive level, gender, temperament, previous pain experiences, family learning, and culture with the largest contributor is the interplay between the cognitive, behavioral and emotional aspects. (Reference: Pain in Infants, Children, and Adolescents 2nd Edition, Chapter 6).

There are many tools available to assess and follow an infant’s and child’s pain; but perhaps the most important tool is the parent’s assessment of behavior changes and the story from the child when it is able to be ascertained. It is important when taking a pain history or measuring the child’s pain to take into consideration the developmental stage of the patient: preschool, school age or adolescence. Also, do not make the assumption that a chronological age necessarily matches with a developmental age.

A commonly used pain scale for infants is the “N-PASS” – Neonatal Pain, Agitation and Sedation Scale. This was first described by Hummel and Puchalski in 2002. The assessment is similar to the APGAR
score commonly used tool in the newborn nursery/labor and delivery areas. The N-PASS scale assesses the infant on: crying/irritability, behavior state, facial expression, extremity tone and vital signs including heart rate, respiratory rate, blood pressure and oxygen saturation and can adjust for prematurity. This tool can be utilized to evaluate the effectiveness of interventions for pain control.

For children, there are a few commonly used pain scales – the FACES, OCHER, and FLACC. The FACES and OCHER tools are a visual analog scale and are presented in a horizontal or vertical line with drawings of faces or photos along a continuum of pain intensity. These can be used for self-reporting by a child as young as three years of age. The FLACC tool – face, legs, activity, crying, and consolability – can be utilized in infants up through childhood and is especially useful in children who are non-verbal or cognitively impaired and unable to self-report pain.

When looking to treat pain, or better yet, control for pain during a medical procedure, it is beneficial to teach the child and parents skills that can be beneficial over the child’s life, especially if the child has a chronic medical condition. These include such techniques as: progressive muscle relaxation, cognitive behavioral methods, art and medical play therapy, biofeedback, distraction, and hypnosis. These modalities have a robust body of literature proving the inherent benefits to helping a child and adolescent through medical procedures that at the same time can be applied globally throughout their lifetime. Furthermore, these are “things” the child CAN DO and the parent CAN DO, thereby empowering them in situations where otherwise they have no control. Child life specialists, psychologists, nurses, and physicians can receive training in any and all of these modalities.

There are obvious reasons to ensure that a pediatric patient, whether an infant, child or adolescent, receives appropriate pain management, especially when that patient has chronic medical condition that will likely necessitate multiple medical procedures over the course of time. It is clear that preventing procedural pain with appropriate pharmacologic and non-pharmacologic treatments will minimize the child’s subsequent pain experience and make it much easier for child, family, and health care providers with repeat procedures. Medical professions caring for these young patients and their families need not shy away from ensuring the pain is managed. There are many “tricks up our sleeves” to help alleviate the experience as painful without having to resort to medications. But even if medications are needed, they can be safely and effectively used. If it hurts in an adult, then it hurts in a child and should be treated. I hope this short summary entices you to do further research on this topic and draw upon other colleagues’ knowledge and skills when caring for the pediatric patient.

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References


CHILD LIFE SPECIALISTS: CORE CLINICAL TEAM MEMBERS IN PEDIATRIC PALLIATIVE CARE

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As pediatric palliative care services expand in hospital and community settings across the United States, child life specialists have become integral members of palliative care teams dedicated to enhancing the quality of life for children with life-threatening health conditions and their families. Palliative care interdisciplinary team members work collaboratively to relieve symptoms, physical and emotional pain, and stress throughout diagnosis, treatment and procedures, home care services, recovery, and end-of-life care. With expertise in children’s unique developmental needs, therapeutic relationships, communication strategies, and the psychosocial impact of hospitalization, child life specialists are strong advocates for children to receive optimal care and comfort.

The American Academy of Pediatrics describes child life specialists as clinicians responsible for promoting play and normalizing childhood, preparing children for diagnosis and treatment utilizing developmentally appropriate information, and developing therapeutic relationships with family to provide emotional support (Pediatrics, 2000). Child life specialists work diligently to normalize the environment for chronically and acutely ill children, focus on children’s strengths, optimize developmental growth, offer opportunities to gain a sense of mastery, and promote self-expression. Their knowledge of specific pediatric needs versus adults needs is imperative for medical teams to provide appropriate care.

The Child Life Council certifies child life specialists based on guidelines for education, training, and professional development. Today child life specialists preferably obtain a masters degree with an area of focus such as child development, education, psychology, or family systems. To receive certification, child life specialists complete an intense 480 hour clinical internship, pass a national certification exam, and continue with professional development (CLC, 2012). Child life specialists often have specialized training in different areas of healthcare, such as oncology, pulmonology, rehabilitation, nuclear medicine, palliative care, or hospice. Child life specialists may also combine degrees with certifications in art, music, dance or aquatic therapy, reiki, infant massage, thanatology, and teaching. Utilizing their expertise, child life specialists serve on hospital committees, train clinicians about pediatric needs, and conduct research to improve pediatric care.

At Elizabeth Seton Pediatric Center in Yonkers, New York, child life specialists are core clinical team members providing pediatric palliative care to all patients. Within this 137-bed pediatric long-term care facility, the clinical team is dedicated to providing palliative care to medically fragile patients via pain and symptom management, stress reduction, and by improving the quality of life for children. This comprehensive program encompasses a network of support services including family centered care, mental health care, social support, child life, art therapy, music therapy, nutrition, rehabilitation, education, and pastoral care (ESPC, 2012).

Children are warmly welcomed to Elizabeth Seton as “residents” whether they are staying for 6 weeks or more for respite care, recovery from surgery, feeding therapy, oxygen weaning, long-term specialized care, or end-of-life care. Patients have common and rare diagnoses, including trisomy 13, trisomy 18, osteogenesis imperfecta, spinal muscular atrophy, neurodegenerative conditions, traumatic brain injury, and premature birth. Children become long-term residents if they are unable to live at home because of intensive medical care needs or complex family dynamics. Typically, 16 to 20 residents on the census are considered end-of-life care due to decline or rapidly progressive life-limiting conditions. Residents live in
of 6 “neighborhoods” in which they receive specialized care from dedicated clinicians attuned to their individual needs in this family-like setting.

In each neighborhood, child life specialists strive to normalize the environment and routines for children, utilize procedure preparation and support in on-site clinics, alleviate anxiety and stress, provide developmentally appropriate stimuli, and support family members as they grieve. Since 2005, Vanessa Andrews has played an integral role on the palliative care team with her responsibilities as a Certified Child Life Specialist, Art Therapist, and Volunteer Coordinator. Andrews’ expertise in child development, chronically ill children, group processing, art therapy, and psychology is interwoven throughout her work supporting and creating opportunities for children to succeed with their different developmental abilities and thrive in this nurturing environment. Members of the palliative care team and Andrews have designed and implemented therapeutic programming for residents, siblings, caregivers, and staff members. These programs include:

Pre-Reflections: When a child’s condition begins to significantly decline, a palliative care team member will meet with neighborhood staff caring for the child. The palliative care team member will provide appropriate information and support in preparation for the child’s further decline, physical changes, family involvement, and the child’s death. With their professional expertise and the nurturing relationships they develop with children in their neighborhoods, intuitively neighborhood staff provide extra comfort to the child.

Reflections: Within 24 hours of a child’s death, a palliative care team member will meet with neighborhood staff in the morning, evening, and night shifts. This meeting is a relaxed forum for staff to process the child’s death; discussing what occurred medically, acknowledging their grief, and reflecting on how the child’s situation was handled and what could be different. Staff members share stories about the child and have an opportunity to openly grieve with each other.

Recordings of Love: Music therapists offer families a legacy building opportunity in the on-site recording studio. Families who wish to be at their child’s side, but are unable because of work or home commitments, can have recordings made singing and talking to the child. The recording is played at bedside for the child to provide comfort, familiarity, and a sense of companionship. Music therapists will also collaborate with the family and child to create a recording together which often becomes a long lasting memory.

Precious Hands: This child life and art therapy activity is a valuable, therapeutic intervention for family members to do legacy-building together when a child is actively dying. Families will create handprints of the child and unique designs. Neighborhood staff may also participate in a “thumbprint tree” in which a tree is drawn with numerous branches, and the child’s thumb is painted on the trunk. The thumbprint tree is available for staff to add their own thumbprints on the branches as they grieve.

Creative Memories: This post memorial scrapbooking project is available in the child’s neighborhood. Family members, staff, and volunteers can each create a personal 8” by 8” page for the scrapbook. This activity provides closure for participants as they create decorative pages, write letters, and include photographs. The book is given to the child’s caregivers.

Memorial Services: A memorial service for every child is held in the hospital’s non-denominational chapel and is open to family members, friends, volunteers, and staff. The hospital will also have a funeral for those families who request it.

In addition to providing therapeutic programming, the Child Life team remains cognizant of other residents’ grief when a peer dies. The team has advocated with fellow clinicians about the significant need to provide developmentally appropriate support to other children processing the loss. Children
develop relationships with each other in their neighborhoods, classrooms, and activity rooms over a period of weeks, months or years at Elizabeth Seton. Andrews explains that while many children are non-verbal and have developmental differences, they too experience loss and grief, detect change when a peer is missing, read caregivers’ body language, and sense others’ grief. Working with these children, the palliative care team often utilizes music therapy, such as a song saying good-bye and representing closure. Child life specialists and music therapists will often co-treat patients functioning at higher cognitive levels.

Together, nurses, physicians, social workers, child life specialists, music therapists, art therapists, recreation therapists, rehabilitation staff, nutritionists, pastoral staff, and volunteers remain sensitive to individual child and family needs and provide nurturing care, comfort, and support to families when children are dying (ESPC, 2012). Reflecting upon the children and families who have benefited from this care, Andrews was especially touched by how palliative care impacted one family:

Yesenia, an infant, was actively dying. Her Spanish speaking parents were tenderly holding her at bedside. Yesenia’s 2-year-old sister, Maria, was in the playroom because her parents felt uncomfortable with her seeing Yesenia die. Despite her young age, Maria knew Yesenia well and loved her important role as a "big sister." Maria asked if she could see Yesenia. Even while playing, it was clear Maria sensed the changes with Yesenia as she listened to people's hushed voices and observed their body language. When I finished handprints with Yesenia and her parents, her mother asked if Maria could also do handprints. I responded, “yes, I’ll bring her in the room.” The parents quickly objected, and the interpreter and I gently explained the materials were at the bedside, and it would be therapeutic for Maria because of her relationship with Yesenia. Their parents agreed. An energetic Maria joined us, and, in typical 2-year-old fashion, she quickly smeared her painted hand on the paper and wiggled it, smudging Yesenia’s tiny handprint. Their mom became distressed and asked to do handprints again, but an uncle quietly spoke up. “No, wait, it looks like Maria is waving good-bye.”

In that instant, the uncle’s astute remark naturally facilitated conversation among the family about Maria’s understanding of the situation, the way the family could support Maria in saying good-bye, and the sense of closure necessary for the entire family to grieve and eventually heal. Despite the developmental differences among sisters and the language barrier for staff and caregivers, this activity of artistic expression served as a non-verbal processing tool for this family as they grieved.

The medical team at Elizabeth Seton remains dedicated to providing excellent care and improving palliative care services for patients and families. As leaders in pediatric palliative care programming, Andrews and the dynamic Child Life team continue to assess current services, refine plans of care to meet individual and group needs, and develop new programming. With siblings experiencing significant grief and loss, the Child Life Program aims to enhance long-term bereavement support programs for siblings in the future.

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References

STEWARDS OF TRAUMA
Robyn Callahan, MSW, LSWAIC
Samantha Wipperman

Helping professionals, including social workers, are becoming more aware of the cumulative effect of vicarious trauma for professionals working with clients who have experienced violence or are in crisis. Vicarious trauma, also known as secondary trauma, first entered the lexicon of psychological conditions nearly two decades ago, when psychologists and co-authors Karen Saakvitne, PhD and Laurie Anne Pearlman, PhD defined such trauma as a “pervasive effect on the identity, world-view, psychological needs, beliefs, and memory systems of therapists who treat trauma survivors” (Richards, 2010, p. 9). Vicarious trauma also has been defined as “an aggregation in the nervous system of the negative impact that is vicariously experienced,” whereas secondary trauma is characterized by “the noticeable sense of overwhelm that therapists may experience as they are serving as a witness to their clients’ experiences” (Rothschild, 2006, pp. 14-15). Regardless of the often interchangeable terminology and nuances in definitions, “a trauma exposure response has occurred when external trauma becomes internal reality” (Van Dernoot Lipsky, 2009, p. 42). The experience and impact of such trauma for stewards of trauma, including social workers and other helping professionals, is significant and potentially devastating.

Trauma stewardship refers “to the entire conversation about how we come to do this work, how we are affected by it, and how we make sense of and learn from our experiences” (Van Dernoot Lipsky, 2009, p. 6). Levine (2005) also speaks to this sense of trauma stewardship in sharing his response to repeated inquiries as to how he can work with a subject as “morbid” as trauma without becoming burned out or depressed: “Witnessing the transformation that takes place in people when they master their traumas has proven to be a deeply sustaining and uplifting experience, both professionally and personally” (Levine, 2005, p. 2). Rather than demonstrating a sense of isolation from his work with traumatized peoples, he celebrates the “great privilege of his clients letting him walk with them on their journeys” (Levine, 2005, p. 2).

In order to turn a secondary trauma paradigm into a healing paradigm, a multifaceted, proactive approach is warranted. It is imperative to first identify the variables that may put a steward of trauma at risk, address the way a trauma exposure response has manifested in one’s personal or professional journey, and, ultimately, implement the appropriate tools toward wellness and sustainable trauma stewardship. The “depth, scope, and causes of secondary trauma are different for everyone, but the fact that we are affected by the suffering of others is universal” (Van Dernoot Lipsky, 2009, p. 41).

Social workers are daily witnesses to suffering as active change agents, passionate advocates, and empathic listeners who, in particular, face a high level of trauma exposure. According to the Bureau of Labor Statistics, employment for social workers is expected to grow faster than the average for all occupations through 2018. Simultaneously, data developed by the massive Global Burden of Disease study conducted by the World Health Organization, the World Bank, and Harvard University, reveal that mental illness accounts for over 15 percent of the burden of disease in established market economies, such as the United States. Financially, medical expenditures on trauma-related disorders increased substantially from 1996 to 2006, from $46.2 billion to $68.1 billion. (Soni, 2009, p. 1)

Increased awareness and need resulting from a variety of sociocultural conditions today, such as the current economic crisis, a growing elderly population, the return of military personnel, and violence, result in a population with increased needs that is more apt to seek out mental health services focused on primary trauma, which can result in secondary trauma issues for the provider. The primary predictor of a secondary trauma response among mental health workers is the amount of hours per week spent working with traumatized people—the number, or percentage, of trauma cases on a mental health professional’s
caseload (Bober & Regeher, 2006, p. 7). In summary, the greater the amount of trauma exposure, the greater the risk of a trauma response.

Another noteworthy variable in navigating the trauma terrain is the role of “empathy.” While a necessary component of an effective therapeutic relationship, empathy also can be a contributing factor to a secondary trauma exposure response. Empathy is a complex, multifaceted construct consisting of behaviors, experienced emotions, and an individual’s personality. It often is considered to be a state in which the helper, without judgment, enters the private world of the client. An individual’s innate capacity for empathy naturally may guide him or her to pursue a career as a helping professional.

An invaluable tool, empathy allows helping professionals to relate to those in their care with an understanding of what they are feeling. Yet, empathy can function as a double-edged sword. “Therapists suffer in their work as a result of unconscious empathy, that is, empathy processes that are outside of the therapist’s awareness and therefore outside of his or her control” (Rothschild, 2006, pp. 10-11). In essence, there is a risk of becoming a prisoner of someone else’s nervous system for often the most effective therapists are those who have an enormous capacity for both feeling and expressing empathy. This mirror effect can manifest as a form of contagion effectively putting the professional a greater risk for secondary trauma.

The concept of empathy is highly linked to the concept of trauma mastery, a sophisticated coping mechanism, implemented either consciously or unconsciously, in which an individual seeks to re-create situations similar to a personally traumatic incident but attempts to achieve a different, more positive outcome this time (Van Dernoot Lipsky, 2009, p. 156). Just like possessing a large propensity for empathy may draw people to a helping profession, attempts at trauma mastery may do the same. An individual may seek to work in a field that is directly connected to an earlier trauma in life. For example, a former victim of domestic violence may seek to work as a victim advocate or work in child welfare.

Van Dernoot Lipsky (2009, p. 156) emphasizes that if trauma mastery is “consciously sought with insight, mindfulness, and honesty, it can be a mechanism for healing.” However, if mastery is attempted with a lack of awareness and intention, it potentially can produce a loss of control, a state of disempowerment. Worse, “…we can end up reinforcing feelings of being overwhelmed or lacking power; at its extreme, unconscious trauma mastery may even increase our risk of physical harm or exposure to dangerous situations” (Van Dernoot Lipsky, 2009, p. 156). When trauma mastery is approached mindfully, it has the potential to serve as a powerful tool in a helping professional’s toolbox.

Experts in the field of trauma study have seen examples of vicarious trauma result in the same type of posttraumatic stress disorder experienced by those who experienced it directly. Unlike most survivors of primary trauma, however, professionals exposed to secondary trauma may or may not be able to identify the impact of their work and can overlook the symptoms of their exposure (Richards, 2010, pp. 10-11).

The ways in which secondary trauma can manifest itself range from psychological stresses and disorders to physical ailments. The 16 signs of a trauma exposure response outlined in the book Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others (Van Dernoot Lipsky, 2009, pp. 47-113) are as follows:

- Feeling helpless and hopeless
- Sense that one can never do enough
- Hypervigilance
- Diminished creativity
- Inability to embrace complexity
- Minimizing
- Chronic exhaustion/physical ailments

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• Inability to listen/deliberate avoidance
• Dissociative moments
• Sense of persecution
• Guilt
• Fear
• Inability to empathize/numbing
• Anger and cynicism
• Addictions
• Grandiosity: an inflated sense of importance related to one’s work

It is important for social workers and other helping professionals to remember the following: Whether you identify with many of the warning signs, a few, or none at all, you are more than okay. It is perfectly normal to have a response to trauma exposure. This means you still have the capacity to connect your internal world with your external reality (Van Dernoot Lipsky, 2009, p.48). Indeed, awareness of the manifestations these variables have in a practitioner’s personal and or professional life serve as the first step to dismantling damaging behaviors and crafting a path toward healing.

All of the warning signs of trauma exposure response potentially can cultivate and perpetuate one another. In his book Healing Trauma: A Pioneering Program for Restoring the Wisdom of Your Body, Peter Levine (2005) notes that when the body experiences trauma “both mind and body mobilize vast amounts of energy in preparation” (pp. 2-3) to deal with the threat. Without an opportunity to discharge that stored energy, “the body holds onto that high-energy, ramped-up state” (p. 3).

In humans, undischarged residual energy can become the catalyst for deep-rooted trauma. Many of the trauma responses outlined earlier are manifestations of this stagnant, trapped energy. Moving into a place of healing requires a strategy for managing one’s energies in a way that supports overall balance, as well as an avenue for catharsis.

Levine offers hope in a strategy for healing trauma through somatic processing. The premise of this approach is an analysis that the core of traumatic reaction is essentially physiological, and it is at this level that healing begins. Somatic processing methods employ a variety of techniques to ultimately liberate the energy that has become frozen as a result of trauma. The goal is to return the nervous system to its natural, resilient, and self-regulating state. This mind-body healing paradigm is explored further in the developing field of psychoneuroimmunology, which addresses the impact of mental and emotional states on physical health and the immune system. Here again, a therapist’s self-awareness plays a vital role of responsibility to help facilitate the patient’s ability to explore the interconnectedness between state of mind and physical climate.

With increased awareness of the root causes of secondary trauma, stewards of trauma, who witness suffering and crises, might attempt to avoid its impact. However, as noted by many researchers, those who serve in such roles are unlikely to be able to avoid secondary trauma entirely. “The best hope for working with trauma in a sustainable way is often cited to be the development of regular wellness practices and a network of support that can help to restore balance” (Richards, 2010, p. 11). Mindfulness meditation, in particular, has been presented as a very effective means of practicing self-care with the additional benefit of enhancing communication and connection with clients.

Irving, Dobkin, and Park (2009), authors of Cultivating Mindfulness in Health Care Professionals: A Review of Empirical Studies of Mindfulness-Based Stress Reduction (MSBR), explore the benefits of mindfulness meditation as it relates to health workers. Epstein, as cited in Irving, Dobkin, and Park (2009), defines mindfulness as “a logical extension of the concept of reflective practice, consistent with being present in everyday experience and open to all thoughts, actions, and sensations” (p. 61).
Extensive research on the bridge between meditation and medicine offers another illuminating definition of mindfulness as the awareness that is evoked through intense attentiveness, with deliberation, in the present, and non-judgmentally open to the moment by moment unfolding of experience. The mindful practice of creating space for inquiry, choosing one’s focus, building compassion and community, finding balance, and, ultimately, a daily practice of centering oneself (Van Dernoot Lipsky, 2009, pp. 147-233) can enhance a helping professional’s communication with clients, as well as help to keep the boundaries clear between work and home life.

As effective trauma stewards, helping professionals such as social workers repeatedly are presented with an opportunity to reconcile the fullness of life, both the great suffering and the great beauty, to witness great change and transformation, and, ultimately, are reminded of the great strength and resiliency of the human spirit.

Robyn Callahan, MSW, LSWAIC, understands the importance of treating the whole person when seeking personal health, wellness, and balance in life. In addition to her MSW, she completed Clinical Training in Mind/Body Medicine at Harvard Medical School and postgraduate training in Chinese medicine and meditation in the Henan province of China. She incorporates her skills to facilitate physical, emotional, and spiritual healing in her clients. She can be reached at www.NWInteogedHealth.com.

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Abstract:
Purpose of review
This article is aimed to review updated research on end-of-life care sedation (EOLC-S) for children and aspects surrounding this issue.

Recent findings
Prevalence of EOLC-S for children may vary across countries on account of cultural differences, in terms of settings, legal issues, and perceptions about EOLC-S, which lead to variation in patient selection and management. Although home is the preferred place of death for families, research shows hospital settings and ICUs to be the most frequent places where children die. Data on how to define refractory symptoms and update research on drug selection and dosing are lacking. Nature of symptoms at end of life (EOL) is described for cancer patients, but few articles are focused on nononcological conditions. Decision making at EOL is commonly discussed with families but children are less frequently involved.

Summary
A thorough search of databases was conducted for articles published in the last year. We found few articles describing EOLC-S as a last resort. But how, when, and by whom a symptom is defined as refractory, is not well established. Aggressive symptom management at EOL along with advanced care planning conducted by pediatric palliative care teams could diminish EOLC-S. More research is needed.

Who is the audience for this information? Providers and ancillary staff who care for children with medical complexity who have intractable symptoms and are near the end of their lives will definitely want and need to read this. While in the US this would apply mostly to inpatient providers, in Western Europe palliative sedation has been utilized in the home setting. Because pediatric palliative sedation is infrequently utilized, expertise in this area is sparse. This article helps fill in some gaps.

What is special about this article? The authors review the pitifully small amount of research that has been published about palliative sedation in the pediatric population. As with many other aspects of pediatric palliative care, because of the paucity of research with children, we are often left depending on extrapolation of adult data and experience. The authors review the adult data that document no shortening of lifespan when palliative sedation is used correctly. The bibliography is particularly rich, annotated, and prioritized, and includes references on definitions and components of palliative sedation, and the available literature on pediatric palliative sedations.

Where and how can I apply this information? Palliative sedation in the pediatric setting should be provided by trained providers after thoughtful consideration, including the family and child as appropriate. Any programs putting together a policy or practice guideline will want to review this article for consideration of defining suitable children, definition of intractable symptoms, pharmacologic interventions, and ethically valid informed consent. One of the most important points is that aggressive
symptom management by trained providers, along with advance care planning, will in many cases obviate the need for pediatric palliative sedation.

My thoughts: We recently had a child where palliative sedation was used; possibly for the first time in our organization. We identified the need for a guideline and expert training in pain/symptom management for our providers and nursing staff caring for the patient and family. We also noted missed opportunities for inclusion of this option as part of the advance care plan.

Shortly after this case, two of our providers returned from the Children's Hospitals and Clinics of Minnesota Pediatric Pain Master Class. They raved about the course and the need for continuing education training for themselves and others. Our goal is to ensure that every suitable child has access to a pediatric provider(s) skilled in pediatric pain and symptom management, decisional support, provision of palliative care, and advance care planning. For very complex children such as those needing palliative sedation, consultation should also be sought from those with specific palliative care training such as providers with board certification in hospice and palliative care.

In general, these decisions should not be “ad hoc” or done surreptitiously. Involvement of the child with capacity, the family, the health care team, and generally the bioethics committee will ensure an ethically sound decision and thoughtful treatment plan. I was on the ethics committee of the NHPCO when it developed a palliative sedation guideline (Kirk TW, Mahon MM. NHPCO position statement on commentary on the use of palliative sedation in imminently dying terminally ill patients. *Journal of Pain and Symptom Management* 2010;39:914-923). At the time, I didn’t think that the pediatric community was quite ready for inclusion of children. Now I think that, not only is the pediatric palliative care community ready, but it is also eager for guidance.
Items of Interest:
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. Subjects and Contributors for Future Issues of This Newsletter. In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, pain and symptom management for children with life-threatening illnesses and their families, complementary therapies, memory building and legacy making, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, and the role of pediatric palliative and hospice care in creating systems to support children, families, and the community. (Please note that you can visit archived issues of this newsletter at www.nhpco.org/pediatrics.) For future issues, we are thinking about addressing subjects such as integrating volunteers and ancillary services in pediatric palliative/hospice care.

If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Maureen Horgan at Maureen.Horgan@providence.org; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

2. Register Now and Save for NHPCO's 13th Clinical Team Conference and Pediatric Intensive. Registration is now open for the 13th Clinical Team Conference and Pediatric Intensive, “It’s About How We CARE: Collaborate, Assess, Relieve, Evaluate,” at the Walt Disney World Dolphin Hotel in Lake Buena Vista, Florida. In addition to the conference, NHPCO and ChiPPS are proud to announce a new educational opportunity: the Pediatric Hospice and Palliative Care Training, a two-day Preconference Seminar on November 3-4. And, of course, there is a full Pediatric Intensive track at the 13th Clinical Team Conference, November 5-7, 2012. Want to learn more about the wide range of offerings? Download the CTC brochure (PDF) for a look.

The Pediatric Hospice and Palliative Care Training is specifically designed for hospice and palliative care clinical staff who are seeking intensive preparation to expand access of pediatric services and will be taught by expert interdisciplinary pediatric hospice and palliative care faculty. The Training includes:

- Principles and Standards of Practice
- Delivery Models
- Ethics, Decision-Making, and Advance Care planning
- Childhood Development in Health and Illness
- The Spectrum of Complex, Chronic and Fatal Conditions
- Assessment and Management of Pain
- Symptom Management
- Psychological Support of the Family and Community
- Bereavement Care
- Structure and Support of the Interdisciplinary Team

Download the CTC Pediatric Intensive registration form – Act fast and register before August 15, 2012 to receive early bird registration rates!
3. NHPCO Webinar - Pediatric Palliative Care: Putting Standards into Practice.
Every hospice and palliative care program should be prepared to provide quality care for patients of all ages. In an effort to improve care across the continuum, the ChiPPS Quality Workgroup recently collaborated with NHPCO to review and update the Pediatric Standards and incorporate them within the larger NHPCO Standards of Practice for Hospice Programs. This Webinar, Pediatric Palliative Care: Putting Standards into Practice, will examine how putting the Standards into practice can enable practitioners and organizations to uphold the highest quality of care throughout the lifespan. In addition, faculty will discuss each of the nine standards and highlight some of the major differences and considerations including Concurrent Care for Children.

This not to be missed Webinar, taught by Brenda Blunt, MSN, RN, CHPPN, CCRN, RNC, Clinical Manager for Gilchrist Kids (Gilchrist Hospice Care) and Sarah Friebert MD, FAAP, FAAHPM, Director and Founder of Haslinger Family Pediatric Palliative Care Center, will be offered September 13, 2012, from 2:00 pm - 3:30 pm ET. CE/CME is offered for Counselor, Nurse, Physician and Social Work disciplines. Learn more and register online.

4. Save The Date. On October 25 & 26, 2012, there will be a Pediatric Palliative Care Conference on Bridging the Gaps in Pediatric Palliative Care at Providence Sacred Heart Children's Hospital in Spokane, Washington. The organizers describe the conference in the following way: The image of bridges seems appropriate as we see the kids we serve and their families at the center of our care, the reason that brings all of us together. But we do have gaps that hinder us from achieving the best care possible. Through the conference sessions we hope to address how we can bridge these gaps to provide better care. The conference includes many disciplines, e.g., physicians, nurses, social workers, and therapists, as well as parents/families of palliative care patients. The conference is interactive and will allow participants to share with each other. For additional information, contact Deborah Rose MN RN CNS, Coordinator Sunflower and Forget-Me-Not Programs, Providence Sacred Heart Medical Center & Children's Hospital, 101 West Eighth Avenue, Spokane WA 99204, Tel. 509-474-2806.

5. Reader's Corner. Our Reader's Corner column, like the one in this issue, provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net.

6. CureSearch Website now in Spanish. CureSearch for Children's Cancer has translated the Foundation's website, www.curesearch.org, in Spanish, making medical content about children's cancer available to parents and families whose children have cancer. Users will find that the entire site has been translated, while maintaining easy-to-use navigation and simple illustrations that depict medical tests and procedures. Content on the site is housed in four main categories: Medical Information, Research, Coping with Cancer, and Getting Involved.
7. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

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 CHIPPS2@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 further materials and resources of interest.