



E-NEWS

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Issue Topic: Overcoming Barriers to Pediatric Palliative Care

Welcome to the sixteenth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter addresses issues associated with overcoming barriers to pediatric palliative care. The articles in this issue describe some experiences of family members when they encounter what they perceive as barriers to care, as well as views of professional contributors who address various types of both barriers and facilitators to pediatric palliative care. Here you will find links to a PDF collection of articles on these topics that have been contributed by family members and professional colleagues. In addition, this issue also includes three resource lists from ChiPPS: one for professionals; one for family members; and a brief list of selected books for children with annotated descriptions of each title.

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 Communications Work Group, co-chaired by Christy Torkildson and Maureen Horgan. We are happy to welcome Maureen here as new Co-Chairperson of this Work Group. Mary Kay Tyler, our former Co-Chairperson, is now Co-Chairperson of the ChiPPS Leadership Advisory Council. We wish both Maureen and Mary Kay all the best in their new posts and responsibilities.

Comments about the activities of ChiPPS, its Communications Work Group, 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.



Issue #16:

Overcoming Barriers to Pediatric Palliative Care

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

Can Anyone Hear Us?

p. 4

Azu Nieves, LMSW, CT

Ms. Nieves shares her pain and isolation as she faced a parent's worst nightmare. She brings a raw emotion and brutal honesty to the barriers she encountered during her son's illness and his death. We hope her story will provide all our readers with insight and provide stimulus for provocative discussions to improve our services for the children and families we serve. This article includes a note from the editors.

Barriers to Accessing Pediatric Hospice and Palliative Care as Viewed by Members of an Interdisciplinary Team

p. 8

Donna Armstrong, MSW, CSW

A pediatric home hospice and palliative care team was surveyed regarding their thoughts on barriers to hospice and palliative care for families. Team members included nurses, social workers, chaplains, administrators, and a physician.

Are Pediatricians a Barrier to Pediatric Palliative Care?

p. 10

David Korones, MD

Dr. Korones shares his journey as a pediatrician and the many barriers to pediatric palliative care including the "abject fear of 'palliative care' and misunderstanding among health care providers and families regarding just what it is and why one would need a team of experts to provide it." It is this barrier that is the focus of his report.

Dealing with Kids Dying

p. 13

David A. Sine, MD

Dr. Sine speaks of his experiences as a pediatric resident and in his words, "I decided to write this article initially for myself as a way of dealing with dying children." We think his experience will touch many of you.

Improving Access to Pediatric Palliative Care by Hospital-Community Partnerships

p. 16

Suzanne S. Toce, MD

Dr. Toce provides us with an excellent overview of organizational and system barriers while focusing on how to improve access to pediatric palliative care. She provides several examples and links to resources to help you improve access and services for the children you serve.

Neonatal Palliative Care: What are the Barriers and Facilitators in Clinical Practice?

p. 21

Victoria Kain, RN, MN, PhD

Dr. Kain, an experienced neonatal intensive care nurse and researcher states, "When mentioned in the same sentence, the words 'neonatal' and 'palliative care' may be an oxymoron for many of us. Why is this, when one considers that more children die in the neonatal period than at any other time in childhood?" She reports on her research focused on "what barriers neonatal nurses perceive to neonatal palliative care, and furthermore, what facilitates it."



***Supporting Families of Children with Life-Limiting Medical Conditions
Who Must Make Difficult Care Decisions***

p. 24

Lori McCullough, MA, MSW, LISW-S, and Tammy Young, RN, MS, CNP

Ms. McCullough and Ms. Young discuss decision-making, the challenges faced by healthcare providers in assisting families in making decisions, and the role of the "clinical facilitator" to help overcome the barriers facing both families and healthcare providers.

Reader's Corner

p. 27

Suzanne S. Toce, MD

Dr Toce provides an overview of a current addition to the literature pertaining to pediatric palliative care.

Three Resource Lists from ChiPPS

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Pediatric Resources for Professionals

Pediatric Resources for Families

Children's Books on Death-Related Issues

Items of Interest

p. 35

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

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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its 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.



CAN ANYONE HEAR US?

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June 2002. My son, Ommy, 22 years young. A beautiful, healthy, handsome, intelligent, thoughtful young man. A loving and caring son. A loyal friend. He'd had a lump on his back for about a year before he thought to tell me about it. The MRI revealed what "looks like cancer." I turned to my son and he looked like he had just seen a ghost. In that moment, he went from a strong, strapping young man to a scared child. His eyes were like saucers, his lips devoid of color. I'm not sure how long we sat there, but when I looked up at the doctor, I saw his mouth moving but I couldn't hear anything he was saying. Finally, my brain clicked on and I asked, "Are you saying that my son has cancer? Are you sure? Are those his results in front of you? Could this be some mistake?" "No," he replied, "it looks like cancer and if he were my son, I'd want him at a major cancer treatment center in New York City." Process, Azu, it is critical that you process this information. You are his mother, you need to take charge here. Get yourself together, NOW!!! "Could you refer us to someone there?" He said he didn't personally know anyone there, but would write down the name and phone number of the top orthopedic oncologist. He added that I would probably have to wait a few weeks to get an appointment. I asked for my son's MRI results, thanked him, and we walked out of his office. I couldn't look at my son because I knew that if I looked at him, I would shatter into a million pieces and I knew that if we were really facing cancer, I needed to put all those feelings in a place inside myself where they would not interfere with what lay ahead.

My precious child was diagnosed with Ewing's sarcoma (a childhood form of bone cancer) and he had surgery. They removed everything visible. The doctor told me that if they discovered in surgery that the cancer had spread, the survival rate dropped from 80% to 40%. It had metastasized into both of his lungs. He also added, in a low voice, that if the cancer recurred after surgery, chemo, and radiation, this type of cancer would not respond to chemo a second time. I heard his words and filed them in the darkest recess of my being. Ommy would be blasted with the strongest protocol they had available at the time. He is young, they said, and otherwise healthy. He should do okay. Through the coming months of watching my child in and out of the hospital, vomiting, being isolated when his cell count was low after chemo so he would avoid an opportunistic infection, unable to do what his friends were doing—I would repeat these words to myself: "He's young and otherwise healthy, he'll do okay. My son MUST survive this, I just have to believe this, keep my wits about me and be strong."

December 2002. Post-surgery, five months of chemotherapy and one month of radiation when his skin was burned and he had a scar from his shoulder halfway down his back. He had lost all of his hair and his eyebrows. His self esteem took a beating, but he was not defeated. His next set of scans and blood work revealed no signs of the cancer. He was clean!! We had a celebration of life party for him. We all wore red for victory and power, and blue for peace and tranquility. We laughed and spoke of the ordeal that was now behind us and a thing of the past.

October 2003. Ten months later. My office phone rings. It is my son. "Mom, it's back." I knew, but didn't want to know. "What are you talking about, what's back?" "The cancer, Mom, it's back. This time it's going to kill me." "How do you know it's back?" "Because it's the same kind of pain but it's on my hip this time. It hurts like hell, Mom." "Okay, my dear child, let me call the hospital and make an appointment. It could be anything, don't think the worst." But it was the worst. The cancer had returned in his hip as the doctor put it, "like a house on fire." My son, my beautiful young son, sitting in front of the doctor in a wheelchair because he couldn't bear the pain in his hip. The social worker and the physician's assistant were also in the room. I knew it couldn't be a good thing that all these people were in the room, especially the social worker. My son with a look of pure terror on his face, hands clasped on his lap. The doctor looked at him, then at me. "He is a very, very sick young man. We need to discuss advance directives." I looked at my



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son, and he looked at me. "Pay attention Mom, because I don't understand what's happening here." We filled out the paperwork, where he named me as his health care proxy. I explained DNR to him, and he said whatever I wanted was what he wanted. I heard a sound like that of a wounded animal, which started like a low keening and rose to a deep suffocating sound as if someone were being choked and were gasping for air. I then realized it was coming from my throat. How could this be happening to my child? How can I be strong for him and help him on this journey if I fall totally to pieces? But how could the core of my being not burst apart and splatter all over the world if I lost my son, my only child? The child I gave birth to, cared for, loved, was a part of my soul? How would I be able to go on, get up in the morning, if anything happened to my boy? Looking over at him and seeing the mounting fear on his face was enough to bring me back to my body. The focus now: how could I make sure he was comfortable and pain free as we traveled this road?

He coughed up blood and went into respiratory distress. They put him into the ICU where I stayed with him day after day. They needed to rule out blood clots in his lungs, and if he made it through the next 48 hours, he would be moved into a room on the pediatric unit. He made it. Once he was settled into a private room, his team came in to see us. It must have been our regular doctor's day off because the attending was someone we had not seen before. Clearly, this doctor was not prepared to talk about what was happening or my son's needs and options. This doctor looked scared as he spewed mumbo jumbo that neither my son nor I understood. He mentioned something about "hospice and a representative coming in to see us." When my son asked what was hospice, the doctor whispered something unintelligible that we couldn't even hear. It was left to me to explain to my son that when a doctor felt they had exhausted all cure-oriented treatment and a person had six months or less to live, they would refer to hospice. He asked me if he was going to die. I said yes, that he was going to die. As I said the words, I felt myself starting to die inside. He begged me to please not send him to hospital "X." How could I deny his request? I promised I would not. I climbed into bed with him; we held each other and cried. After we cried, we made jokes about something I can't remember now, then we laughed until we started crying again. What, I wondered, were our options now? And how could I keep my son comfortable and pain free?

It quickly became clear that my son's doctor was not comfortable on the subject of "what's next?" Finally after about ten days, the case manager explained that they were going to discharge him home or to hospital "X," whichever one we chose. I asked her if her institution had any hospice beds, and she said they did not. I asked why not, when so many died there every day. She could not really answer and said only that they referred people to hospital "X" and a few others. Even though my son had so little time, knew the doctors, and had made friends with the staff of nurses his own age and other patients on the unit, he could not stay. And all the case manager could say was "I'm sorry" as she looked down at the floor.

My boss told me not to dismiss hospital "X" without first touring the place, which we did together. When asked, the hospital "X" rep said that they had young people and when I asked to tour that unit, they changed the subject. The place was beautiful, peaceful, and spotless. It was also amazingly quiet, without the usual noise and chaos that usually surrounds nursing stations. But, of course, I saw the people who were dying, lying in beds in rooms around the nursing station, looking like cadavers. Hopelessness and tremendous sadness enveloped me like a shroud. My son could not spend his last days in Hospital "X," he would die faster if he saw what I was seeing. What then were the REAL options for a dying young man in the last days of his life?

Back at the hospital, they asked us what we had decided. We did not know. My boss suggested bringing my son to the nursing facility where we worked. That was an option I had not even considered, but without other real options, it was the only solution that made sense. I worked there, the staff knew my son, he would get great care and attention, and I would be there with him.



This was the best of the few alternatives we had. The facility was not an end-of-life facility, and the staff was not trained in cancer care in its late stages, but because I worked there, we got a private room with two beds. The social work staff had stocked up the closet with all kinds of goodies for us to eat at night when we couldn't sleep, and we had lots of blankets and bed linens which were scarce. But three weeks later, my son took a turn for the worse and the doctor on duty said he would have to be transferred back to the cancer treatment center because they did not have the capability of treating him and he would not make it through the night if we kept him there. Back we went. This time his regular oncologist came to see us, the man we had come to know, respect, and really admire for his honesty and compassion. He took both of my son's hands in his, looked him right in the eyes, and cried with us as he delivered the verdict that it was only a matter of time because the cancer was so widespread. Ommy, my son, looked at his doctor and asked if he could stay there where he felt safe and where he could get all the medication he needed for the excruciating pain he felt, and the doctor said yes. "Yes, you can stay here until you die. Your Mom can stay, too. I will make sure you stay right here."

Some relief at last. My son would be well taken care of physically, get all the pain medication he needed, and be surrounded by staff who knew what they were doing when it came to responding to pain. My son's doctor most likely had to fight a battle when he made his announcement to his superiors given that they had no "hospice" beds and this was a "treating" hospital as opposed to a hospice. From this last admission to his death, it was a little over one month. My son died peacefully four months before his 25th birthday, not even two years after initial diagnosis.

Editors' Note:

In correspondence with the author of this article after its acceptance, she offered some additional comments as she looks back on her experiences. We offer here a summary of her responses to two questions.

Question #1: What would have provided more support, looking back as a bereaved mom?

A united family and friends can provide great support.

If the staff weren't so afraid to talk about death, that would have helped me. I didn't want to put it all on my friends so it would have been great if an outside person at the hospital would have or could have listened to our fears, questions, etc.

Doctors, please be honest with parents or patients who ask directly if they are going to die. If the patient or family asks, they really, really, really need to be honest. This gives the patient/family a chance to tie up loose ends, do things at the end of life that they want (my son wanted to go back to his apartment one last time and we were able to accomplish that), see people who live far away, ask for/receive forgiveness, etc. I am aware of cultural differences and some cultures not wanting to know, etc., but I'm talking about direct questions

The honesty of doctors and those in the medical profession goes a long way in helping those who are facing death and their caregivers prepare and wrap up what needs to be done. And here I'm talking about those who ask specific questions. I understand some people don't want to know and some families are afraid. Once they are informed of their prognosis, some people want more information and others don't. This is targeted to doctors and health care professionals dealing with those people who want more information. Doctors (i.e., oncologists, etc.) also need to take some sort of class in medical school where they deal with their own feelings around death so they are able to help their dying patients.



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Question #2: What has helped me since the death of my son?

While my son was dying, I was a student at Hunter School of Social Work. After he died, I focused on finishing my masters. He said to me "Mom, please don't stop now. Get that masters for you and for me." I can't stress enough how difficult it was to focus on school while grieving and my professors were a great help.

Another thing that has really helped me heal is helping others facing the same thing. To know that you are not alone and that others have gone through or are going through something similar is so comforting. That is my mission.

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BARRIERS TO ACCESSING PEDIATRIC HOSPICE AND PALLIATIVE CARE AS VIEWED BY MEMBERS OF AN INTERDISCIPLINARY TEAM

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A home hospice and palliative care team was surveyed regarding their thoughts on barriers to hospice and palliative care for families. Team members included nurses, social workers, chaplains, administrators, and a physician.

1. What are the barriers to families accessing hospice care?

- Lack of knowledge of regarding hospice care
- Fear of accepting diagnosis (denial)
- Fear of the word "hospice"
- Belief that hospice care is only for adults
- Desire to do everything possible to help child and belief that choosing hospice care means giving up
- Lack of understanding of support provided for hospice children
- Prognosis - children are more difficult to prognosticate than adults and do not fit neatly into the traditional six months or less criteria
- Lack of appropriate referrals
- Financial support of program/lack of reimbursement stream for children who do not meet the traditional hospice criteria
- Families' acknowledgment of need for hospice care
- Inner resistance on the parents' part to considering the possibility of their child declining or dying someday—how it is presented to families makes all the difference
- The comfort level of physicians in explaining to parents what to expect without taking away their hopes—if done well it will open the door to pediatric hospice care
- Availability of hospice programs which accept children
- Current agencies/resources in place (in some states the hospice Medicaid benefit locks a patient out of all other programs, forcing them to choose between hospice and other resources which are needed)
- Cultural barriers
- Lack of understanding regarding insurance coverage

2. What are barriers to families accessing Palliative Care?

- Lack of understanding of palliative care on the part on parents and other medical professionals
- Knowledge and or/existence of programs
- Palliative care is the perfect bridge to transition from acute/aggressive care to hospice care
- Availability of pediatric palliative care programs—both in the hospital and the home setting
- No local providers for this type of care (MDs)
- Also may be viewed as "giving up"



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3. What changes need to be made to improve access to pediatric palliative care and hospice care for families? (Changes can be on a policy level, institutional level, etc).

- Increase education to community physicians
- Offer palliative care training to pediatricians
- Increase education to agency staff on pediatric hospice and palliative care
- A Medicaid Waiver to cover Palliative care
- More education within the community on both hospice and palliative care including eligibility criteria
- Education at medical schools for physicians to have a better capacity to grasp when palliative care is indicated and to be able to communicate that effectively to the parents
- Easy access to informational pamphlets regarding palliative care and/or hospice care at children's hospitals, pediatricians' offices, etc.
- All physicians treating pediatric patients should be required to receive training on grief—how illnesses, death, etc., affect all members in the family
- Education for medical staff on how the illness affects the child and the importance of respecting the child's desires and wishes specifically where he/she wants to die
- Changes in the reimbursement structure
- Very important to call program a name other than "hospice" and emphasize supportive role
- Involvement with children and medical care team at the time of diagnosis

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ARE PEDIATRICIANS A BARRIER TO PEDIATRIC PALLIATIVE CARE?

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I suspect the readers of this newsletter know all too well the many and formidable barriers to rendering palliative care to our young patients. Not a day passes that we don't encounter many or all of these obstacles: the challenges of assembling a multidisciplinary team to provide care for a relatively uncommon problem, the minimal reimbursement for the huge amount of time and personnel required to give good care, the uncertainty among family and providers regarding when to intervene, the relative lack of an evidence base for both medical and psychosocial aspects of relieving suffering in children, and the abject fear of "palliative care" and misunderstanding among health care providers and families regarding just what it is and why one would need a team of experts to provide it.

It is this last barrier that I would like to speak to in this brief report. It was not that long ago that I was a barrier to pediatric palliative care. I was a veteran pediatric oncologist, had cared for all too many children who had died, and had also managed their considerable symptoms along the way. It was part and parcel of my job and I felt quite capable of doing it. So when a resident once suggested that we involve the palliative care team to assist in the care of a patient of mine who was declining and unlikely to survive, I bristled. I recall thinking, "I don't need them. I know how to talk to this patient and family. I know how to provide comfort. I will know when it is time to say 'enough is enough'." I recall fearing that the team would undermine my relationship with the family, and talk them into putting limits on the aggressiveness of my patient's care when I didn't think such limits were appropriate. In fact, the palliative care team did not take over, did not "pull out the ET tube," but sat with the family . . . and listened. And so my education in the value of this discipline began. But how do we convince our colleagues in general pediatrics and the many pediatric subspecialties of the same thing?

It helps to understand the barriers, which I think fall into 3 broad categories: (1) a subset of us think that we are well-versed in palliative and end-of-life care and do not require the help of a subspecialty service; (2) large numbers of us profess to a lack of experience and comfort addressing palliative care issues (and may tend to put it off or avoid discussion of these issues); (3) many pediatricians do not understand exactly what palliative care is. Regarding the first barrier, there may be a sense among pediatricians that providing comfort to our ill patients comes naturally. While this hypothesis has not been extensively studied, a 2001 survey of pediatric oncologists regarding their knowledge and attitudes about palliative care suggests that this is the case.¹ In that survey of 250 pediatric oncologists, 96% rated their communication skills with dying patients and their families high, 86% considered themselves very competent or competent coordinating care of dying patients, 95% considered themselves skilled in making the transition from disease-targeted to more comfort-oriented care, and 82% felt they were good mentors to trainees in these areas. Yet 69% admitted to having anxiety discussing these issues with children and their families, and incredibly, only 10% reported having had any formal training or coursework in end-of-life care.

As for the second barrier, there are data to suggest that we pediatricians are not that experienced, not that comfortable, and not that skilled at rendering palliative and end-of-life care. For example, as noted above, 85-95% of pediatric oncologists rated themselves skilled in palliative and end-of-life care. Yet in a separate study conducted around the same time, only 38% of families who lost a child to cancer felt that the discussion with their health care provider about their child's terminal illness went well.² Families also reported that high percentages of children who died of cancer suffered from fatigue, pain, nausea,



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vomiting, diarrhea, and constipation; furthermore, many of these symptoms were not recognized or successfully treated by their pediatricians.³ Contro et al surveyed 450 pediatric health care providers at Stanford in 2004 and found that 30-70% of pediatricians, residents, and nurses admitted they are inexperienced treating symptoms of dying children and communicating about end-of-life issues with dying children and their families.⁴ They also reported on 68 family members of 44 children who died; recurrent themes among these bereaved survivors included poor delivery of bad news, inadequate pain control, failure to address the needs of siblings, and inadequate care and support at home.⁵

These data suggest that we pediatric health care providers are a barrier to our patients getting the support and services they need: we profess (and our patients corroborate) a lack of experience and comfort in managing pain and other symptoms, particularly at the end of life. We also are not comfortable with the arduous task of communicating with families in that difficult transition from disease-targeted to end-of care.

Regarding the third barrier, a series of studies have been published that suggest that we pediatricians do not fully understand what palliative care is. Davies et al queried pediatricians and nurses regarding potential barriers that interfered with their providing optimal end-of-life care to children. Fifty-five percent cited an "uncertain prognosis," 51% felt the family was not ready to acknowledge an incurable condition, and 47% reported time constraints.⁶ Sizeable numbers also reported insufficient knowledge of palliative care in general, insufficient knowledge of pain management at end of life, conflict among family or between staff and family regarding goals of care, and inadequate support services. (All reasons we in palliative care would quickly jump up and shout that this underscores the need for formal pediatric palliative care involvement!) In another recently published survey, Thompson et al queried 303 pediatricians regarding their understanding of what palliative care is and when they refer children for palliative care services.⁷ Forty-two percent defined palliative care as hospice care, and 26% did not know what it is. Only 49% had ever referred a child to a palliative care service and 29% did not even know whether there was a palliative care service in their region.

Interestingly, even the words "palliative care" seem to alienate health care providers. Fadul et al surveyed 140 oncologists and oncology mid-level providers about their comfort level referring a patient on active treatment but with a guarded prognosis to a team named "supportive care" versus a team named "palliative care."⁸ These practitioners were far more likely to refer to a "supportive care" team than a "palliative care" team (80% versus 44%), and preferred the term supportive versus palliative in discussing goals of care with patients (57% versus 19%). They also felt that the term "palliative" versus "supportive" equated with end-of-life/hospice care (57% vs. 15%), caused decreased hope in patients/families (44% vs. 15%), was a barrier to referral (23% vs. 7%) and caused distress to patients (33% vs. 4%). In a similar survey of pediatricians and families of ill children, both pediatric health care providers and parents said they were more likely to use the services of a program identified as "supportive care" than "palliative care."⁹ But importantly, once they read a description of the services provided, the name did not really matter. Taken together, the data culled from these studies suggest that pediatric health care providers still do not appreciate the potential broad application of palliative care services and tend to equate it with end-of-life care. In addition, even the very name of a program using the words "palliative care" can be an obstacle to getting children and families the services they need.

So how do we overcome these obstacles: a well-meaning pediatric workforce that generally acknowledges a lack of skill and experience in palliative and end-of-life care, and a broad, deep-rooted misunderstanding that palliative care is equal to end-of-life care. It will take a lot of work: patience and understanding that a change in culture can take a generation, not just a few years; persistence on our part – reminding our colleagues we are available and eager to assist in the care of their most challenging patients; good and collegial service when we are consulted; training – from the medical school curriculum, to residency, fellowship and even faculty; careful and judicious use of the term "palliative care team"



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(many pediatric palliative care teams use acronyms such as PACT or different names altogether such as Footprints or Butterfly).

Is there any hope for lasting, meaningful change? Absolutely! The evidence is already coming in. Pediatric palliative care programs are springing up all over the country and world, hospitals are linking with community services, curriculae are incorporating pediatric palliative care at all levels of training. Wolfe et al cite a change in attitude and understanding at their own institutions over the past 10 years.¹⁰ They noted that in their institutions hospice discussions occur earlier, do-not-resuscitate orders are written sooner, ICU deaths are less common, and parents report their children experienced less suffering. In Florida, a Medicaid waiver has enabled the creation of a pediatric palliative care program entitled "Together for Kids." Children with life-threatening illness are eligible for enrollment, and can receive a broad array of hospice-like services, even though their life expectancy may be far greater than 6 months.¹¹ Since its inception in 2006, enrollment has quintupled, referrals by physicians have increased, children are enrolled earlier in the course of their illness, and patient and child satisfaction is exceedingly high. Other states are following suit.

Ten years ago I was a subspecialist who was very leery of palliative care. Was my eventual appreciation of its integral role in the care of chronically ill children an aberration? I think not. Through good service, education, and expertise in relieving suffering in children and their families, pediatric palliative care teams will continue to demonstrate their value to our patients and colleagues, and the barriers will continue to crumble.

References

1. Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 19:205-212, 2001.
2. Wolfe J, Klar N, Grier He, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 284:2469-75, 2000.
3. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 342:326-333, 2000.
4. Contro NA, Larson J, Scofield S, et al. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics* 114:1248-52, 2004.
5. Contro N, Larson J, Scofield S, et al. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med* 156:14-19, 2002.
6. Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics* 121:282-8, 2008.
7. Thompson LA, Knapp C, Madden V, Shenkman E. Pediatricians' perceptions of and preferred timing for pediatric palliative care. *Pediatrics* 123:e777-782.
8. Fadul N, Elsayem A, Palmer JL, et al. Supportive versus palliative care: what's in a name? *Cancer* 115:2013-21, 2009.
9. Boldt AM, Yusuf F, Himelstein BP. Perceptions of the term palliative care. *J Pal Med* 9:1128-1136, 2006.
10. Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol* 26:1717-23, 2008.
11. Knapp CA, Madden VL, Curtis CM, et al. Partners in Care: Together for Kids: Florida's model of pediatric palliative care. *J Pal Med* 11:1212-1220, 2008.

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DEALING WITH KIDS DYING

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"You're a doctor . . . you are sworn to save lives!" (from a mother with her dying son).

"Doctor, you need to come see Johnnie now! I think his time has come"

I decided to write this article initially for myself as a way of dealing with dying children. I had to deal with a number of deaths during my residency and found I had received very little training or guidance. It is a topic not frequently discussed during training.

From acute unexplained death in the emergency room, to unexpected complications and death in the neonatal ICU . . . to kids dying in the pediatric ICU after extended attempts to save them, to those chronic kids (cancer, cystic fibrosis)—the ones you cannot help but become attached to, in part because they spend a great deal of their lives in the hospital.

"I'm coming back home next week again!" (An oncology patient told he had to come back to the hospital in a week for chemo). These encompass your continuity patients, the heme/onc kids, the renal kids, the HIV+ kids, the CF kids, and many others.

How do we deal with it? We just do! Who do we have to help us or guide us? A scarce resource exists. No one seems to want to deal with a dying child. With this paper I hope not only to share some feelings but to provide some guidelines in caring for these children, yourself, and others.

Jesus is a young boy with a tentative diagnosis of interstitial pulmonary fibrosis. He is your typical Hispanic boy who speaks more English than he lets on. I met him in a routine well child check and he ends up in my continuity clinic. I see him regularly over the next two years for various concerns and a trusting bond develops. He has the unfortunate history of experiencing the death of his two older siblings with the same disease he now faces.

I consulted a number of physicians and performed med-line searches to try to find something that could help him; nothing turns up. I watch him stabilize over the next few months on steroids; then a gradual deterioration begins. He has multiple admissions and on discussion with his mother, a DNR is established; as the transplant team has again denied his case. I arranged in-home hospice, but very few of the care-givers spoke Spanish and the mom continues to call me.

Shortly thereafter, I was on call in the neonatal ICU, dealing the best I could with the death of a post op heart baby whom I had been up with the entire night. We have also just returned from the birth of an unexpected Trisomy 13 baby. I then get a call from the emergency room that Jesus is there and told the nurse to call me. The ER attending is very upset that a DNR patient is in the emergency room. His mother brought him because she was scared he was going to die and she's not ready for it. Thoughts begin to surface and overwhelm me:



What am I going to do? I'm stressed out enough dealing with this 'crumping' kid and the baby that just died. I've been awake for over 24 hours. What am I going to say to the mother; or to Jesus for that matter? Does Jesus even know that he could die today? Will I be able to look into his eyes?

In our busy overextended days there are times when you just have to stop—sit back and assess the situation. Dealing with death does not follow an algorithm.

I see him in the ER and begin the treatments as I had during his past three exacerbations. He doesn't respond like he has before and I know, in my heart, he won't make it through the day. I discuss the options with Jesus and his mother and they want to be admitted; they have only been with hospice for one week and don't feel comfortable. Jesus feels "safe" in the hospital.

Unfortunately, despite excellent people working with hospice, a relationship takes time to develop. Health care providers cannot expect families to simply 'move on' and work with new people/new supports. It is a gradual process that needs to start as early as possible. Each new case becomes very individualized.

Again, upon evaluating his response to therapy I realized he would not "pull through" this time. I could also see it in his mother's eyes—a mother who has already lost two daughters and was going to lose a son today. I thought to myself: 'How could anything I deal with even compare to what she is dealing with.'

Realizing death is imminent is an important time. The family may or may not realize it and therefore must always be told. Family members need to be summoned and comfort measures become ever more crucial.

Pain at death needs to be avoided. Pediatrics has always been a field where pain has universally been underestimated and insufficient narcotic analgesics given.

I continue to work in the NICU while in the back of my mind I torture myself, 'If only I had tried harder, found something, fought for transplant, could I really give him too much morphine? Can I save his little sister or is this poor mother going to lose faith in me. After all, why shouldn't she? I have done nothing for her son except tell her he is going to die today.'

Bereaved families turn to the health care provider for support/comfort, especially with a terminally ill child who may have spent a great deal of time in the hospital. Before helping others one must read into our own feelings/experiences. Many memories are evoked and our own personal tragedies must be resolved. Anger is aroused secondary to the sense of failure and hopelessness, and this combined with painful memories, tends to make the caregiver have further feelings of incompetence and withdraw from the family. The emphasis needs to be refocused on healing.

This is a common experience in pediatric residency, yet often it is the least experienced individual who deals with the family. The way we deal with death has a great impact on the child, the family, the staff, and your own self.

I continue to make myself go and see him despite my inner turmoil. He continues to fight for each breath but actually looks somewhat more comfortable. He looks at me, smiles, then kisses his mom and dies in her arms

The most involved physician should be at the bedside for death or very soon thereafter as this demonstrates sensitivity.



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I later pronounce him (there is no rush) and talk to the family. I want to cry but something makes me hold back. Is it wrong? I am the doctor after all! Does it make me weak? I can't help it, I cared for this boy for two years and now he is gone. I cry. I hug the mother and hold Jesus' hand, which is already getting cold.

There is a belief that the physician must restrain feelings and not burden the family more. However, surveyed parents stated that they felt increased support from the doctors who cared with tears in their eyes. It's okay to cry. You should use the child's name, be genuine, touch, and say you are sorry. It is a time to remember and share certain qualities.

Two comments are made which I will always carry with me:

Father: "Jesus really liked you. He would pray every night that you would be the one; the one to help him, to save him. He trusted you."

Parents often blame the physician as you "did not save my child." It's your job. You swore an oath to save lives. This is all a reaction to the loss of a child and should inspire you to be consoling/supportive.

Mother: "Jesus is free now. He knew he was next. He watched his sisters; the watching is done. He's free and not hurting . . . I thank you for that."

You must reassure yourself and the parents that everything was done. I spoke with the brother and the sisters and gave them my card to call anytime.

You can share your personal death experiences and must always attend to the surviving kids. In addition, you should call the parents for follow up.

Bereaved families turn to the physician for support/comfort when dealing with death and dying of a child, especially one who is terminally ill. It is a common experience in pediatric residency and an uncommon experience in training. The way you chose to deal with it will have great impact not only on you but also on all those around you. It is ok to care.

I finish my day, 36 hours after it started, and go running . . . nowhere in particular; that's just the way I deal with it.

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IMPROVING ACCESS TO PEDIATRIC PALLIATIVE CARE BY HOSPITAL-COMMUNITY PARTNERSHIPS

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In the United States, 2 to 3% of children live with conditions that are disabling or significantly affect activities. On any given day 5,000 to 8,600 would benefit from palliative/hospice services (Friebert, 2009). Less than 10% of children who die, have had the benefit of such services. There are many barriers to access and utilization of palliative/hospice services by children and their families. In this article, I will review barriers and discuss collaborative strategies to overcome barriers and improve the experience of children with life limiting conditions and their families.

Barriers to access: Imagine an infant with severe congenital anomalies or a teenager with cancer no longer responsive to treatment. Where and by whom do they get treated? The circle of care might include (most importantly) home, and the tertiary hospital and ER, community hospital and ER, the community physician office, home nursing, home hospice/palliative care, community pharmacist, durable medical equipment providers, emergency medical technicians, school nurse, and the list goes on. Is excellent pediatric palliative care provided by educated, trained caregivers in all settings? What are the barriers to access to quality pediatric palliative care?

- Geographic: Specialized services are available primarily in large cities with children's hospitals. Children and their families may reside far from such services.
- Education/training: Children often receive care from providers who are not optimally trained in pediatric palliative care. For those hospice/palliative care agencies belonging to the NHPCO who provide pediatric services, only ~1/3 have pediatric trained staff and physicians. Across sites of care, there are few pediatric and hospice providers who are trained in pediatric palliative care. Pediatric palliative care is rarely part of medical and nursing education or licensing requirements. Also there is limited on-call availability, lack of awareness of pediatric services that exist, and poor ability to respond to child and family spiritual and psychosocial issues.
- Cultural issues: Prognosis and ability to predict death is even less certain in childhood conditions than in adults. Indications for palliative care are unclear and trajectories of illness are unpredictable. Families and/or health care providers may not accept that palliative care is indicated or beneficial. There may be poor agreement with treatment goals between the family and the health care team. Families may see referral to palliative/hospice care as "giving up hope." Providers, particularly physicians may see referral as reflecting failure to cure, and may be resistant to refer until the child is very close to death. Families from different religious/spiritual and ethnic backgrounds may view end-of-life care very differently. Communication with families whose primary language is not English is even more challenging for children with life-limiting conditions.
- Finance: Pediatric palliative care is expensive (more expensive than comparable care for an adult) and poorly reimbursed. Reimbursement through the hospice benefit requires expectation of death within 6 months and, in general, forgoing expensive therapies for treatment or palliation. Reimbursement is based on what is allowed not what is needed.
- Organizational: The fact that services are frequently not provided by the same personnel or organization as the child moves through phases of illness and sites of care provides a major barrier to excellent consistent coordinated palliative/hospice care. There are few strategies designed to optimize communications between providers at different sites of care. Because



pediatric palliative care is very time consuming, many community physicians may not feel that they can take on such patients.

- Developmental: Childhood illnesses leading to premature death are rare and have unique aspects. Tools for symptom assessment and management, advance care planning, and quality improvement are limited. Child development and family dynamics are central and treatment plans should be appropriate to the child's developmental stage and updated accordingly. Evaluation and research concerning pediatric palliative care are clearly different from that concerning adults and have their own challenges. There is a high child and family burden of research and quality improvement. Families may decline to participate. Institutional Review Boards may be reluctant to include children in studies because of the high burden. Hence progress in the field is hampered.

Quality should not be site or provider specific. The structure and process of care should lead to optimal outcomes of comfort, child/family satisfaction, appropriate care utilization, efficient use of resources, and stable family function.

Tertiary care and community organizations providing palliative/hospice care:

- Tertiary care centers/children's hospitals: Most children appropriate for palliative care are cared for at some time at a specialized center. They are a great source for referrals. Specialists with expertise in pain and symptom management are frequently located there. Intensive medical and symptom treatment is available. Ancillary subspecialty providers, such as art or music therapy, pediatric OT/PT/speech therapy, etc., are available. These centers frequently are involved in training of physicians, nurses, social workers, chaplains and other pediatric providers. They are positioned well to provide education in pediatric palliative care. There is access to medical interpreters. The fact that care is predominately inpatient is a challenge and providers may lack an outpatient viewpoint. Care may be fragmented if there is poor communication and coordination with other hospital providers and with community providers. In children's hospitals where success may be defined by cure, providers may be inexperienced in and resistant to palliative care.
- Pediatric home nursing organizations: Staff providers are skilled at managing chronic pediatric disease. They are frequently located in the community where children live. Expensive palliative treatments can continue and will be reimbursed. Some of the challenges include the fact that they rely on referrals and may lack pediatric palliative care expertise. Chaplains, social workers, PTs, interpreters, etc., are not usually available or reimbursed. There is rarely supervision by a physician skilled in pediatric palliative care.
- Community hospices: There is expertise in outpatient pain and symptom management and palliative care principles. The team is interdisciplinary as is optimal for provision of palliative care. Care is family centered and community based. There is provision of family support before, during, and after death. Unfortunately, hospices that primarily care for adults may be poorly prepared to care for pediatric patients and their families. Not only does this impact care but it also can cause a high level of staff stress. As with home nursing, these organizations rely on referrals. Parents may see hospice as "giving up" and not choose hospice. As hospice has its own medical and other services, long standing relationships with the primary care team may be severed. Hospice regulations and reimbursement require expectation of death in 6 months. As noted above, care of children is more expensive and may not be covered under the traditional amount of the hospice benefit.

Collaborative strategies to overcome barriers

- Geographic: Specialized pediatric palliative care/hospice services are rarely available in most communities. Community providers and home health or hospice/palliative care organizations can develop formal or informal relationships with pediatric palliative care providers at children's



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hospitals/tertiary centers or specialized pediatric hospice/palliative care organizations. Consider contracting with a skilled pediatric palliative care provider as the pediatric medical director of a community organization. Telemedicine can help bridge the distance gap. Consider establishing regularly scheduled outreach clinics and/or consultative contractual arrangements. When a child is referred for services within the community, request on-site outreach education to help community providers care for the child and family. Phone conferences and consultations should be used liberally. These strategies are particularly helpful for hospices and other organizations that rarely care for children with life-limiting conditions. In some areas there will be regionalized pediatric palliative care services to either provide direct care or consultation. Some sample models exemplifying hospital community collaborations include:

- FOOTPRINTS across Missouri <http://www.glennon.org/CurrentMagazine/footprints.htm>
 - Minneapolis Children's Hospice <http://www.childrensmn.org/communities/hospice.asp>
 - Edmarc Hospice for Children <http://www.edmarc.org/>
- Educational: Include pediatric palliative care education in provider education, licensing, and recertification. Include pediatric palliative care interest groups in professional organizations. There are many opportunities for collaboration between skilled pediatric palliative care providers and community care providers. Involve tertiary care providers in the education of community care providers. The tertiary center and community organization could co-sponsor an Initiative for Pediatric Palliative Care retreat (<http://www.ippcweb.org/>). Train the trainer models can help disseminate expertise in pediatric palliative care. Ask community organizations to fund attendance by their staff at pediatric palliative care conferences. Provide pediatric palliative care educational material for parents and staff at sites of community care. Have community home nursing and hospice organizations offer medical and nursing student rotations and mentoring. Involve community pediatric hospice staff in the in-patient hospital care of their patients and medical teaching. Expert pediatric palliative care providers can guide organizations to have appropriate written pain and symptom assessment and management guidelines.
 - Cultural: Broaden community awareness of benefits of pediatric palliative care. There should be a culture shift where pediatric palliative care is equated to "best quality care" for children with life-limiting conditions who meet criteria. It is important that data and evidence as well as stories are used to educate physicians and other health care providers about benefits of pediatric palliative care. Providers, particularly physicians, should see the results of intensive palliative care as a success for them, the child, and the family. Community faith providers and cultural organizations can be great partners to ensure culturally and religiously sensitive practices. Some success stories include:
 - State coalitions of organizations working together to advocate for access to pediatric palliative care such as Children's Hospice and Palliative Care Coalition in California (www.childrenshospice.org), the Washington DC Collaborative (www.dcppcc.org), and the Pennsylvania Children's Hospice and Palliative Care Coalition (www.pa-chapcc.org)
 - Working with "celebrities" to increase awareness: Melissa Gilbert, Johnny Depp, and many NHL players advocate for pediatric palliative care
 - Coalitions of organizations with the same goals such as Partnering for Children: Children's Hospice and Palliative Care Coalition in California, NHPCO, National Hospice Foundation work together to provide <http://www.partneringforchildren.org/>
 - Broaden your reach: Engage the community. Collaborate with schools, funeral homes, faith groups, EMS groups, and parent groups.
 - Financial: Community providers in collaboration with pediatric palliative care specialists can work with legislators and third party payors to broaden availability and funding of hospice/palliative services so they are not limited to 6 months and are appropriate to the individual child's needs. It is important to collect data about cost of end-of-life pediatric care using different models of care.



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Some community organizations have been expert at seeking innovative funding solutions. Expand and disseminate demonstration projects and different models of care provision. Reimburse time for team communication, sibling support, and ancillary personnel involvement.

Some sample financial strategies include:

- Seattle Children's and Blue Cross worked to have a patient/family centered benefit with improved quality of life and family satisfaction with no increased cost
 - Some large hospices fund prenatal and pediatric palliative care under the umbrella of adult services
 - NHL Canadian teams partner with pediatric hospices for fund raising
 - HCFA funded Program for All-Inclusive Care for Children (PACC) demonstration projects (New York, Florida, Kentucky, Colorado, Virginia, Utah)
 - State Medicaid Waivers providing funding for pediatric palliative care through demonstration projects (Florida, Colorado, California)
- **Organizational:** No one organization or provider can adequately care for these challenging children and their families. Collaborate and avoid turf battles. Accept that one size does not fit all. Different children and families need different services and models of care. Different organizations within different communities will naturally develop different models of care. As long as the child gets the appropriate, quality services, the model of care is immaterial. Provide advanced care planning and a treatment plan that is continuous and coordinated across sites of care. Communicate with family and all providers who may interact with the child/family. Provide a key contact person to coordinate care. Families prefer the involvement of a key contact person. Involvement of a physician has been shown to reduce pain and symptoms. Identifying a physician champion in children's hospital will further development of pediatric palliative care and will be a great source of referrals. Have continuity team in the tertiary hospital to provide continuity between admissions. Have the tertiary care continuity team available for consultation by community care providers. Do not sever relationships as the child moves into different care models. Some tools and strategies that enhance communication and care coordination include:
 - Written "advanced directives." Use a communication tool such as the **POLST**, **Physician Orders for Life Sustaining Treatment**, **FOOTPRINTS** Advanced Care Plan Orders, or the **AAP** Emergency Information Form for Children with Special Needs.
 - Consider a care coordination model such as **FOOTPRINTS**
 - Train home health pediatric nurses at the tertiary center in pediatric palliative care principles
 - Work with EMS districts to agree to transport and treat according to the care plan
 - Ensure that access is 24/7/365. Ensure cross coverage by pediatric trained staff
 - Send home prescriptions for meds that treat expected symptoms
 - **Developmental:** Recognize the unique aspects of pediatric palliative and end of life care. Tertiary centers in collaboration with schools of public health can further knowledge in the field by helping develop and disseminate predictors of childhood death, site of death, and financial aspects of pediatric end-of-life care. Guidelines or triggers for eligibility for palliative care and hospice care should be standardized and implemented. There is need for development of appropriate models of care for in-hospital and community hospice and palliative care. More tools are required to facilitate decision making, and assessment and management of pain and symptoms. Despite the fact that children are encouraged to participate in decision making, there is a need for tools to help assess their capacity and competency. Tools for recognition of imminent death should be developed. There are standard quality assessment tools for adult but not pediatric palliative and end of life care. Quality improvement will be greatly improved by tools that assess the quality of life, quality of care, and satisfaction with pediatric care. In addition, assessment of organizational success of pediatric palliative care programs is needed. Educational strategies to enhance attitudes, skills, and behaviors need to be developed and implemented along with evaluation tools



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to evaluate educational adequacy. Behaviors are much more challenging to change and measure. As most children who need palliative care have been seen at a tertiary center, identification of children is most efficiently done there. This makes collaboration between community and hospital organizations and providers even more important. As community providers are familiar with the family and community resources, they can help inform this process, gather community support, and raise awareness.

Collaboration between hospital and community organizations and providers is not only possible and beneficial, it is necessary to ensure provision of expert pediatric palliative care.

Resources

- [Caring for Kids: How to develop a Home-based support program](#) by NHPCO's Children's Project on Palliative/Hospice Services (ChiPPS)
http://iweb.nhpc.org/iweb/Purchase/ProductDetail.aspx?Product_code=820577
- *CHIPPS Compendium of Pediatric Palliative Care* (www.nhpc.org)
- Committee on Bioethics and Committee on Hospital Care, AAP. Palliative Care for Children. *Pediatrics* 2000; 106:351-357
- Committee on Pediatric Emergency Medicine, AAP. Emergency preparedness for children with special health care needs. *Pediatrics* 1999;104:e53
- Contro N, Larson J, Scofield S et al, Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med* 2002;156:14-19
- Culturally effective pediatric care. *Pediatrics* 1999;103:167
- Davies B, Sehring SA, Partridge JC et al. Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics* 2008;121, 282-288
- DNR in the school setting. *Pediatrics* 2000; 105: 878-879
- Ferrell, Coyle. *Textbook of Palliative Nursing*. Oxford
- FOOTPRINTS tools from SSM Cardinal Glennon Children's Hospital and Seattle Children's
<http://www.promotingexcellence.org/i4a/pages/Index.cfm?pageID=3310>
- Friebert S. NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America. April 2009.
- Goldman A, Hain R, Liben S. *Oxford Textbook of Palliative Care for Children* Oxford
- Himmelstein et al, Pediatric Palliative Care. *NEJM* 2004;350:1752-62
- Institutes of Medicine. *When Children Die: Improving Palliative and End of Life Care for Children and Their Families*. http://www.nap.edu/catalog.php?record_id=10845 (free summary on line)
- *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. (BS Carter, M Levetown, ed.), Johns Hopkins University Press
- **POLST, Physician Orders for Life Sustaining Treatment** <http://www.ohsu.edu/ethics/polst/>
- Toce S, Collins MA. The FOOTPRINTS model of pediatric palliative care. *J Palliat Med* 2003;6:989-1000
- UNIPAC series (www.aahpm.org)

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NEONATAL PALLIATIVE CARE: WHAT ARE THE BARRIERS AND FACILITATORS IN CLINICAL PRACTICE?

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When mentioned in the same sentence, the words “*neonatal*” and “*palliative care*” may be an oxymoron for many of us. Why is this, when one considers that more children die in the neonatal period than at any other time in childhood? This question has driven my research through the ethical and emotional minefield of developing palliative care models for babies who are not expected to survive. It would be a reasonable assumption that when death becomes inevitable for a dying newborn, that decisions to prolong suffering be reassessed and a transition to palliative care be considered (Carter, 2004). However, such an assumption is not this straightforward. In my clinical experience as a neonatal intensive care nurse, I was often intrigued as to why my colleagues embraced “aggressive” curative models of care so readily, yet often felt uncomfortable about palliative models of care. The purpose of my research agenda, therefore, has been to investigate what barriers neonatal nurses perceive to neonatal palliative care, and furthermore, what facilitates it.

In recent years, palliative care for the neonatal population has become increasingly topical and part of the lexicon of contemporary neonatal nursing practice. An evidence-based protocol (Catlin & Carter, 2002) is available to inform this model of care, yet in reality, provision of palliative care to newborns is ad hoc (Cignacco & Zeitschrift-Für, 2004; Maginnes, 2002). In the majority of neonatal intensive care units (NICU) within developed countries, any newborn weighing more than 500 grams or a gestation of 24 weeks is likely to be offered intensive care (Yu, 2005). Given this, ethical treatment dilemmas are endemic to most NICUs and appear to be driven by issues relating to advances in technology and pharmacology. This has resulted in increasing numbers of newborns presenting to the NICU, and the literature is saturated with escalating controversy over whether this type of healthcare is in the best interests of these newborns (Hack, Friedman, & Fanaroff, 1996; Kain, 2006, 2007a). Each of these babies pose the same question to healthcare staff: How can we decide in his or her best interests (Baumann-Holzle, Maffezzoni, & Bucher, 2005).

Complicating these ethical concerns is the notion that the death of a newborn in this highly curative environment is a failure of medical science (Lo, Quill, & Tulsky, 1999). Whilst this highly technical environment saves the lives of newborns, healthcare needs to provide for the needs of newborns who will die before they leave the hospital. Data from the United States report an overall newborn mortality rate of 6.7 per 1,000 live births in 2004 (Dept. of Health and Human Services, 2004), with 20,000 newborns born each year with conditions considered incompatible with life beyond the first year, and are essentially “born dying” (Glick & Merenstein, 2002). These data suggest that neonatal palliative care should be increasingly relevant, yet palliative care principles are inconsistently applied, and in the past two decades there has been growing recognition of the importance of palliative care for newborns with unviable outcomes (Sumner, 2006). Furthermore, inconsistencies in palliative care practice may evolve from the historical association of palliative care with oncology or geriatric patients – not newborns and infants. In my research (Kain, 2008), a survey was developed that was administered to a population sample of Australian neonatal nurses (N=646) (Kain, Gardner, & Yates, 2009) using a pilot-tested instrument (Kain, 2007b) to explore the barriers and facilitators to palliative care practice. Analysis of these data identified 3 constructs that classified the facilitators and barriers to palliative care practice as being about: the organization in which the nurse practices, the available resources to support a palliative model of care, and the technological imperatives and parental demands on clinicians. Following this phase of the



research, a series of focus groups were conducted with neonatal nurses to contextualize these findings to inform healthcare policy.

The overall findings from this research lead to three primary conclusions, the first relating to the organization in which the neonatal nurse practices. Although facilitators were identified at the organizational level to support practice, there were caveats implicit to each of these facilitators that impinge upon adoption of a palliative model of care. Specifically, these caveats can be contributed to the minimal role that the neonatal nurse has in decision making on behalf of dying babies, and their minimal advocacy role. Neonatal nurses reported a sense of powerlessness in facilitating a model of palliative care in the current clinical environment. Although there is support for palliative care, the nursing voice requires fortification in order to advocate effectively on behalf of dying newborns, and to be effective in the decision making process. The second conclusion relates to the resources available to support a palliative mode of care, specifically that the available resources such as physical infrastructure and available staffing were inadequate to meet the needs of dying babies and their families. Furthermore, the lack of engagement in clinical guidelines to support a palliative model of care means that neonatal nurses cannot necessarily accommodate the needs of dying babies and their families.

Finally, the third conclusion related to the moral and ethical concerns raised by the neonatal nurse, raising substantial ethical concerns relating to the technological imperatives used to support life, and the demands made by parents. These issues may be contrary to the values of a palliative model of care, and contribute markedly to the moral distress of caregivers and conflict in the clinical area. I would therefore suggest that the lack of policy to guide the judicious use of technological life support is inhibitory to a palliative model of care. Furthermore, although this research found that parents are informed of palliative care options, and are involved in decision making on behalf of their baby, current organizational processes do not necessarily facilitate the involvement of parents in a consistent and structured manner. I suggest that the demands of parents may result from a lack of information to guide them in their treatment choices.

The overall results from this research have led to a composite understanding of the barriers and facilitators to palliative care practice in neonatal nursing, which may account for the gap between support of palliative care for dying newborns, and the application of this model of care in clinical practice. Translating these findings into policy directives that are applicable to the clinical environment has resulted in the development of recommendations that are aimed at improving palliative care practice in the NICU.

References

- Baumann-Holzle, R., Maffezzoni, M., & Bucher, H. (2005). A framework for ethical decision making in neonatal intensive care. *Acta paediatrica*, 94, 1777-1783.
- Carter, B. (2004). Providing palliative care for newborns. *Pediatric Annals*, 33(11), 770-777.
- Catlin, A., & Carter, B. (2002). State of the art: Creation of a neonatal end-of-life palliative care protocol. *Journal of Perinatology*, 22(3), 184-195.
- Cignacco, E., & Zeitschrift-Für, G. (2004). Recommendations for the palliative care of dying neonates. *Empfehlungen zur Palliativpflege von sterbenden Neugeborenen*, 208(4), 155-160.
- Dept. of Health and Human Services. (2004). VitalStats Perinatal Mortality. http://www.cdc.gov/nchs/datawh/vitalstats/vitalstats_perinatal1.htm.
- Glicklen, A. D., & Merenstein, G. B. (2002). A neonatal end-of-life palliative protocol - an evolving new standard of care? *Neonatal Network*, 21(4), 35-36.



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- Hack, M., Friedman, M., & Fanaroff, A. (1996). Outcomes of extremely low birth weight infants. *Pediatrics*, 98, 931-937.
- Kain, V. J. (2006). Palliative Care Delivery in the NICU: What barriers do neonatal nurses face? *Neonatal Network*, 25(6), 387-392.
- Kain, V. J. (2007a). Moral distress and providing care to dying babies in neonatal nursing. *International Journal of Palliative Nursing*, 13(5), 242-247.
- Kain, V. J. (2007b). Pilot study of an instrument to measure attitudes to palliative care practice in neonatal intensive care nursing. *Collegian*, 14(4), 16-20.
- Kain, V. J. (2008). Developing palliative care models in neonatal nursing : an investigation of barriers and parameters for practice. [QUT Thesis]. <http://eprints.qut.edu.au/17012/>.
- Kain, V. J., Gardner, G., & Yates, P. (2009). Neonatal Palliative Care Attitude Scale: Development of an Instrument to Measure the Barriers to and Facilitators of Palliative Care in Neonatal Nursing. *Pediatrics*, 123(2), e207-213.
- Lo, B., Quill, T., & Tulsky, J. (1999). Discussing palliative care with patients. *Annals of internal medicine*, 130, 744-749.
- Maginnes, E. (2002). Palliative care in the neonatal population. *Neonatal Network*, 21(4), 77-78.
- Sumner, L. (2006). Extending palliative care into pregnancy and the immediate newborn period: state of the practice of perinatal palliative care. *Journal of Perinatal & Neonatal Nursing*, 20(1), 113-116.
- Yu, V. Y. (2005). Is neonatal intensive care justified in all preterm infants. *Croatian Medical Journal*, 46(5), 744-750.

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SUPPORTING FAMILIES OF CHILDREN WITH LIFE-LIMITING MEDICAL CONDITIONS WHO MUST MAKE DIFFICULT CARE DECISIONS

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Many are the challenges that face families who care for children with life-limiting medical conditions. Among the most daunting of these challenges is making decisions related to the care of their seriously ill child, particularly when the choices are not clear-cut and the prognosis is uncertain. As healthcare professionals, assisting patients and families with these difficult decisions can often feel like an insurmountable challenge. The emotionally delicate and complex nature of these decisions make careful management of the process essential to promoting better quality of care for patients and more satisfying outcomes for families and the healthcare team.

There are many factors to consider in laying the groundwork for supporting families through the process of making difficult decisions for their child. Among them are *the characteristics of the clinician facilitator*. Is the facilitator well informed about the child's medical history and current condition? Does the facilitator have knowledge and skills related to assisting families with difficult decision making, including sensitivity to the complex and emotion laden nature of this process; respect for the patient and family's wishes and goals, and an appreciation of the importance of their involvement in the decision making process; and the willingness to invest the time and attention needed to support such a complex process? Facilitation by a team member who has had the opportunity to develop a relationship with the family and has established a degree of trust and confidence is ideal, but may not always be possible depending on the nature of the timeline for the decision—whether this is a sudden more urgent situation requiring a limited timeline for decision making, or a less urgent situation with a more flexible timeline.

A study conducted by UCLA Mattel Children's Hospital lends support to the importance of the characteristics of the clinician facilitator, and the value of a relationship with the family as enhancing communication. This study demonstrated five domains of communication valued in clinicians by patients and families. Questionnaires and interviews were used to obtain the perspectives of children with physician-determined life-limiting conditions and their parents. Relationship building, demonstrated effort and competence, exchanging information, being available, and the appropriate involvement of the family were identified as the prominent qualities of communication that positively affect quality of care (Hsiao et al., 2007). This study reinforces the principle of building an honest, trusting relationship among patients, families, and health care providers as a key component to effective communication that establishes the foundation to assist and support families with difficult decisions.

The current context of the decision is another very important factor to consider in supporting families making difficult decisions for their child's care. As previously mentioned, the child's current medical condition and how that impacts the urgency of the situation and the flexibility of the timeline for the decision must be taken into account. Is this decision prompted by a sudden, unexpected change in the patient's condition during an Emergency Department visit or ICU stay that requires an expedited decision making process? Or has the family arrived at the point of decision after a lengthy hospital stay or a gradual progressive illness in which this decision has been anticipated and considered, and may be of a less urgent nature allowing the time frame for making the decision to be more flexible?



Consideration for *the family context* is imperative in assisting families with challenging care decisions. Family context variables include cultural dynamics and values that impact the family's perception of quality of life and what the family deems as acceptable or unacceptable in relation to the child's care. Cultural awareness informs the facilitator when considering what words or terminology will have the most meaning for the family and be most helpful to them in effective decision making, and which family members or significant persons should be included in or be present for the discussion. Additionally, educational background or potential barriers to the family's comprehension (i.e., intellectual, language, or disability, such as a hearing impairment) should be considered and accommodated.

Dr. Chris Feudtner from Children's Hospital Of Philadelphia highlights the importance of collaborative communication with the family-in-context in his article "Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making." The clinician facilitator's understanding of the differing perspectives and goals of the family members in relation to his/her own goals and perspectives as the clinician is important in enhancing the collaborative process of decision making. Feudtner identifies five tasks distinctive to collaborative communication: establishing common goals that guide the collaborative effort, exhibiting mutual respect and compassion, developing a sufficiently complete understanding of differing perspectives, assuring maximum clarity and correctness of what we communicate to each other, and managing intrapersonal and interpersonal processes that affect how we send, receive, and process information. Dr. Feudtner points out that depictions and perceptions of situations and problems can vary with individual points of view (Feudtner, 2007). Given this, the importance of understanding the family context is paramount to effective facilitation of difficult decision making.

A useful tool for the clinician in organizing a more structured approach for facilitating decision making with the family is *The Decision-Making Communication Tool (DMT)* created by the Seattle Pediatric Palliative Care Project. The DMT provides a simple chart to organize important aspects that contribute to effective support of families facing difficult care decisions for their child. Chart categories include: History of Present Illness, Medical Indications, Patient/Family Preferences, Quality of Life, Contextual Issues, Discussion and Plan.

Assisting patients and families with difficult decision making takes patience and time. We live in a fast-paced society full of technological advancements, in which the human-to-human connection is often lost in the whirlwind of schedules and deadlines. Making the time to develop an honest, trusting, and compassionate relationship can help ease the burden of this difficult process for the family and the patient's healthcare team. Though this article is not intended to be exhaustive in its scope, the authors believe that careful attention to the areas of consideration discussed will serve to enhance the role of health care providers as allies in this difficult and emotionally tender decision making process, prevent families from experiencing the emotional "paralysis" that can occur when faced with these painful decisions, and promote better outcomes for the patient, the family, and the healthcare team.

References

- Browning, DM. (2002). To Show Our Humanness—Relational and Communicative Competence in Pediatric Palliative Care. *Bioethics Forum*, 18, 23-28.
- Browning, DM., Solomon, MZ. (2005). The Initiative for Pediatric Palliative Care: An Interdisciplinary Educational approach for Healthcare Professionals. *Journal of Pediatric Nursing*, 20, 326-334.
- Buckman, R. (2001). Communication Skills in Palliative Care: A Practical Guide. *Neurologic Clinics*, 19, 989-1004.



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- Children's Hospital & Regional Medical Center (2003). *The Decision-Making Tool for Comprehensive Care Planning: Family-Centered Care Team Communication with the DMT*. Retrieved 01/20/2009 from http://www.seattlechildrens.org/our_services/pdf/Decision%20Making%20Tool.pdf.
- Feudtner, C. (2007). Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making. *Pediatric Clinics of North America*, 54, 583-607.
- Field, M., Behrman, R. (2003). *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Report of the Institute of Medicine. Washington, DC: National Academies Press.
- McCann, D., Young, J., Watson, K., Ware, RS., Pitcher, A., Bundy, R., Greathead, D.(2008). Effectiveness of a tool to improve role negotiation and communication between parents and nurses. *Paediatric Nursing*, 20, 14-19.
- Hallstrom, I., Elander, G. (2004). Decision-making during hospitalization: Parent's and children's involvement. *Journal of Clinical Nursing*, 13, 367-375.
- Ross, MH., Valentine, J., Haynes, G., Geyer, JR., Villarearle, N., Mckinstry, B., Varni, JW., Churchill, SS.(2006). The Seattle Pediatric Care Project: Effects on Family satisfaction and Health-Related Quality of Life. *Journal of Palliative Medicine*, 9, 716-728.
- Hsiao, J.L, Evan, E.E., Zelterzer, L.K., (2007). Parent and child perspective on physician communication in pediatric palliative care. *Palliative and Supportive Care*, 5, 355-365.
- Wharton, RH., Levine, KR., Buka, S., Emanuel, L. (1996) Advance Care Planning for Children With Special Health Care Needs: A Survey of Parental Attitudes. *Pediatrics*, 97, 682-687.

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Reader's Corner

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Peace of mind and sense of purpose as core existential issues among parents of children with cancer.

Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC.
Arch Pediatr Adolesc Med. 2009 Jun;163(6):519-24.

ABSTRACT

OBJECTIVE: To evaluate issues experienced by parents of children with cancer and factors related to parents' ability to find peace of mind.

DESIGN: Cross-sectional survey.

SETTING: Dana-Farber Cancer Institute and Children's Hospital, Boston, Massachusetts.

PARTICIPANTS: One hundred ninety-four parents of children with cancer (response rate, 70%) in the first year of cancer treatment. Main Outcome Measure The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being sense of meaning subscale.

RESULTS: Principal components analysis of Functional Assessment of Chronic Illness Therapy-Spiritual Well-being sense of meaning subscale responses identified 2 distinct constructs, peace of mind (Cronbach alpha = .83) and sense of purpose (Cronbach alpha = .71). Scores ranged from 1 to 5, with 5 representing the strongest sense of peace or purpose. One hundred forty-seven of 181 parents (81%) scored 4 or higher for questions related to sense of purpose (mean [SD] score, 4.4 [0.6]). Only 44 of 185 parents (24%) had scores in the same range for peace of mind (mean [SD] score, 3.2 [0.9]) ($P < .001$). In a multivariable logistic regression model, parents had higher peace of mind scores when they also reported that they trusted the oncologist's judgment (odds ratio [OR] = 6.65; 95% confidence interval [CI], 1.47-30.02), that the oncologist had disclosed detailed prognostic information (OR = 2.05; 95% CI, 1.14-3.70), and that the oncologist had provided high-quality information about the cancer (OR = 2.54; 95% CI, 1.11-5.79). Peace of mind was not associated with prognosis (OR = 0.74; 95% CI, 0.41-1.32) or time since diagnosis (OR = 1.00; 95% CI, 0.995-1.003).

CONCLUSIONS: Physicians may be able to facilitate formulation of peace of mind by giving parents high-quality medical information, including prognostic information, and facilitating parents' trust.

Who is the audience for this information? All members of the health care team. It will be particularly helpful for physicians who, because of worry over impact on the parents of hearing bad news, may avoid delving into specific information about the disease and the prognosis.

What is special about this article? It is nice to understand what the parents perceive from the communications of the health care team. While there was a moderate degree of sense of purpose, parents reported low degrees of peace of mind. Parents report being more hopeful after a conversation that includes prognostic information, even if the prognosis is poor. Interestingly likelihood of cure was not related to the parents' peace of mind, but information quality, trust, and prognostic disclosure were.

Where and how can I apply this information? Physicians can feel more confident that prognostic disclosure will help rather than hinder parents' peace of mind. Delivering this information may lead to less uncertainty on the part of the family and may be associated with less use of non beneficial life supporting technology at end of life.



PEDIATRIC RESOURCES FOR PROFESSIONALS

While by no means a definitive list, these are some of the resources recommended by members of the Children's Project on Palliative/Hospice Services (ChiPPS).

ChiPPS is a group of professionals who are working together to enhance the science, practice, and availability of pediatric palliative and hospice care. Since its inception in 1998, ChiPPS has made valuable contributions to the field, including the development of educational materials that can help organizations serve the needs of children more effectively. In addition to these resources, visit the ChiPPS section of NHPCO's Web site: www.nhpc.org/pediatrics.

Web Sites

- Association for Children with Life-Threatening or Terminal Conditions and Their Families (www.act.org.uk).
- Caring Connections (www.caringinfo.org).
- Children's Hospice and Palliative Care Association (www.partnershipforparents.org).
- Children's Hospice and Palliative Care Coalition (www.childrenshospice.org).
- Children's Hospice International (www.chionline.org).
- Hospice Foundation of America (www.hospicefoundation.org).
- The Initiative for Pediatric Palliative Care (www.ippcweb.org).
- Perinatal Hospice (www.perinatalhospice.org).
- Promoting Excellence (www.promotingexcellence.org).

Professional References

- LexiComp Pediatric Dosage Handbook (www.lexi.com).
- Oxford Textbook of Palliative Care for Children (Goldman, Hain, Liben).
- Textbook of Palliative Nursing (Ferrell, Coyle).
- YNIPAC series (www.aahpm.org).
- When Children Die: Palliative and End-of-Life Care for Children and their Families (Field). National Academy Press (www.nap.edu).
- Pediatric Pain Management and Sedation Handbook (Yaster, Krane, Kaplan, Cote, Lappe, Mosby).
- Pediatric Pain & Symptom Management Algorithms for Palliative Care (L Wrede-Seaman). (intelicard.com/hospicekids.html).
- Palliative Care for Infants, Children, and Adolescents: A Practical Handbook (BS Carter, M Levetown, ed.), Johns Hopkins University Press.
- American Academy of Pediatrics Committee on Pediatric Emergency Medicine, AAP. Emergency Preparedness for Children With Special Health Care Needs. *Pediatrics* 1999; 104: 53.
- American Academy of Pediatrics Committee on School Health and Committee on Bioethics, Do Not Resuscitate Orders in Schools. *Pediatrics* Vol. 105 No. 4 April 2000, pp. 878-879.
- American Academy of Pediatrics Committee on Pediatric Workforce. Ensuring Culturally Effective Pediatric Care: Implications for Education and Health Policy. *Pediatrics*, December 2004, pp. 1677-1685.
- American Academy of Pediatrics Committee on Pediatric Workforce, Culturally Effective Pediatric Care: Education and Training Issues. *Pediatrics* 1999; 103:167.



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National Hospice and Palliative Care
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- American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care, Palliative Care for Children. *Pediatrics*, Aug 2000; 106: 351-357.
- Medical Education About End-of-Life Care in the Pediatric Setting: Principles, Challenges, and Opportunities Pediatrics (Olle, Sahler, Frager, Levetown, Cohn, and Lipson), *Pediatrics*, March 2000; 105: 575-584.
- Care of the Dying Child (Goldman, ed.), Oxford University Press, Oxford, UK, 2002.
- Handbook of Childhood Death and Bereavement (Charles A. Corr and Donna M. Corr, editors), Springer Publishing Co., NY. 1996.
- Handbook of Adolescent Death and Bereavement (Charles A. Corr and David E. Balk, editors), Springer Publishing Co., NY. 1996.
- Video: Making Every Moment Count (Leorra Kuttner), Fanlight Corporation.
- Caring for kids: How to develop a home-based support program, NHPCO. [Item 820577; www.nhpco.org/marketplace].
- [Education and Training Curriculum in Pediatric Palliative Care](#), NHPCO. [Item 820285; www.nhpco.org/marketplace].
- Hospice Care for Children (Armstrong-Dailey and Zarbock, editors), Oxford University Press: New York, 2nd edition (3rd edition in press).
- The Deepening Shade: Psychological Aspects of Life-Threatening Illness (Sourkes), Pittsburgh: University of Pittsburgh Press. 1982.
- Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness (Sourkes), Pittsburgh: University of Pittsburgh Press. 1995.
- Pediatric Palliative Care: The Role of the Intensivist (Frankel), *Current Concepts in Pediatric Critical Care*, 2007.
- A Paradigm for Making Difficult Choices in the Intensive Care Nursery (Benitz), *Cambridge Quarterly of Healthcare Ethics*, 1993.
- Family Perspectives on the Quality of Pediatric Palliative Care (Larson, Scofield, Sourkes, Cohen), *Archives of Pediatric and Adolescent Medicine*. 156, January 2002, 14-19.
- Hospital Staff and Family Perspectives Regarding the Quality of Pediatric Palliative Care (Contro, Larson, Scofield, Sourkes, Cohen) *Pediatrics* 2004; 113: 1248-1252.
- Oxford Textbook of Pediatric Palliative Care (Goldman, Haines, and Liben, editors), London Oxford University Press. 2006.
- Food, Toys and Love: Pediatric Palliative Care (Sourkes, Frankel, Brown, Contro, et al), *Current Problems in Pediatric and Adolescent Health Care*, 2005; 35, 9, 345-392.
- Oxford Textbook of Palliative Medicine (Doyle, Hanks, Cherny, Calman, editors), Oxford University: New York, 3rd edition (4th edition in press).



PEDIATRIC RESOURCES FOR FAMILIES

While by no means a definitive list, these are some of the resources recommended by members of the Children's Project on Palliative/Hospice Services (ChiPPS).

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Web Sites

Aiding Mothers and Fathers Experiencing Neonatal Death (www.amendgroup.org).

Offers a free counseling service to parents who have experienced the loss of an infant through miscarriage, stillbirth, or neonatal death. Its main purpose is to offer support and encouragement to parents having a normal grief reaction to the loss of their baby.

Alliance of Grandparents, A Support in Tragedy (www.agast.org).

Produces a quarterly newsletter, and features a section on resources and a place to post memorials.

BabySteps (www.babysteps.com).

Provides resources for parents, siblings and other family members, including a remembrance room, bereavement sharing rooms, and bereavement resource rooms with a section on "do's and don'ts." Other sections of site list literature for adults and literature for children—each offering short descriptions/comments on the many titles listed.

Bereaved Families of Ontario (www.bereavedfamilies.net).

This site of Bereaved Families of Ontario—a longstanding, well-established organization—offers many types of support groups and activities for many different types of family bereavement situations (children, adolescents, parents, etc.). BFO has numerous affiliates throughout the Canadian province of Ontario.

Candlelighters Childhood Cancer Foundation (www.candlelighters.org).

This web site serves as a support group for parents whose children are living with or have died from cancer.

Caring Connections (www.caringinfo.org).

A program of the National Hospice and Palliative Care Organization that offers consumer information for parents of ill children.

Children's Hospice and Palliative Care Association (www.partnershipforparents.org).

This association offers a support network for parents of children with serious illnesses, with access to handouts and discussion forums for parents. Information is available in Spanish.

Children's Hospice and Palliative Care Coalition (www.childrenshospice.org).

This California partnership advocates for legislation and has developed the Partnership for Parents web sites—see the *Partnership for Parents* entry below.



The Compassionate Friends (www.compassionatefriends.org).

This national nonprofit self-help support organization offers friendship and understanding to bereaved parents, grandparents, and siblings.

Dougy Center (www.grievingchild.org).

A nonprofit organization that provides peer and professional support to grieving children. The Dougy Center's mission is to provide a safe place for children and families to share their experiences.

Grief and Loss (www.aarp.org/griefandloss).

The AARP Grief and Loss Program has been in existence since 1973 and offers eCards, online journals, a discussion area, and articles on coping with the loss of specific loved ones.

Hygeia® (www.hygeia.org).

Brings together an international community of families who have endured the tragedy of miscarriage, stillbirth and neonatal/infant loss. Online since 1995 and with over 28,000 members, Hygeia® has become the most enduring program of compassion, empathy and support pertaining to Perinatal loss. There are poems and a place for memories and mementos. There is a 24-hour, toll-free support line, and links to journaling opportunities for healthcare providers. The large database of families allow links between families whose fetus/newborn has a rare condition. Information is accessible in Spanish as well.

Mothers in Sympathy and Support (www.misschildren.org).

A nonprofit, international organization which provides immediate and ongoing support to grieving families, empowerment through community volunteerism opportunities, public policy and legislative education, and programs to reduce infant and toddler death through research and education. Provides information in Spanish.

National Organization of Parents of Murdered Children, Inc. (www.pomc.com).

Provides the ongoing emotional support needed to help parents and other survivors facilitate the reconstruction of a "new life" and to promote a healthy resolution. Not only does POMC help survivors deal with their acute grief, but also with the criminal justice system.

National SIDS/Infant Death Resource Center (www.sidscenter.org).

Provides information and resources (professional and non-professional) about Sudden Infant Death Syndrome, stillbirths, and miscarriages. Provides information in Spanish.

Partnership for Parents/Padres Compadres (www.PartnershipforParents.org/

www.PadresCompadres.org). Excellent online resources for parents whose children have been diagnosed with a life-threatening or life-shortening illness, are receiving treatment, or have died.

SHARE Pregnancy and Infant Loss Support (www.nationalshareoffice.com).

SHARE's mission is to serve those who are touched by the tragic death of a baby through miscarriage, stillbirth or newborn death. Its web site offers a packet of grief literature, information on local chapters, bimonthly newsletter, and resources.

Subsequent Pregnancy After a Loss Support (www.spals.com).

SPALS features an e-mail based, self-help listserve service for people who are pregnant or hoping to be pregnant after an infant or prenatal loss.

Sudden Infant Death Syndrome Alliance (www.sidsalliance.org).

Another good general resource on SIDS.



Survivors of Suicide (www.afsp.org).

This is a comprehensive site for survivors of loss from suicide. It contains a directory of SOS chapters, excerpts from the organization's quarterly newsletter, and suggestions for suicide survivors. Local and national programs, tips for coping, and information about the causes of suicide, etc. are all presented in a clear and easily navigable site.

Winston's Wish (www.winstonswish.org.uk).

The premier British support group center for bereaved children and their families. Runs weekend residential camps, offers telephone and online resources, works in collaboration with educators and members of the community, and has a splendid book by J. A. Stokes: *Then, Now and Always—Supporting Children as They Journey Through Grief: A Guide for Practitioners*.

Books

Ash, L. (2004). *Life Touches Life: A Mother's Story of Stillbirth and Healing*.

Beggins, Jeanne P. (2004). *A Book of James*.

Bramblett, J. (1991). *When Good-Bye Is Forever: Learning to Live Again after the Loss of a Child*.

Crider, T. (1996). *Give Sorrow Words: A Father's Passage Through Grief*.

Daher, D. (2003). *And the Passenger was Death: The Drama and Trauma of Losing a Child*.

DeFord, F. (1997). *Alex, the Life of a Child*.

Fleming, D. (2005). *Noah's Rainbow: A Father's Emotional Journey from the Death of His Son to the Birth of His Daughter*.

Koppelman, K. L. (1994). *The Fall of a Sparrow: Of Death and Dreams and Healing*.

Kushner, H. *When Bad Things Happen to Good People*.

Leach, C. (1981). *Letter to a Younger Son*.

Orloff, S. & Huff, S., editors. (2003). *Home Care for Seriously Ill Children*.

Sarnoff Schiff, Harriet – *The Bereaved Parent*. Penguin Books.

Schrauger, B. (2001) *Walking Taylor Home* [ISBN 0-8499-1703-4].

Smith, G. H. (2006). *Remembering Garrett*.

Stinson, R., & Stinson, P. (1983). *The Long Dying of Baby Andrew*.

Wagner, S. (1994). *The Andrew Poems*.



CHILDREN'S BOOKS ON DEATH-RELATED ISSUES

Selected and Annotated by Charles A. Corr, PhD, CT

Picture and Activity Books for Preschoolers and Beginning Readers:

Carney, K. L. (1997-2001). *Barklay and Eve Activity and Coloring Book Series*. Dragonfly Publishing Company, Wethersfield, CT (277 Folly Brook Boulevard, Wethersfield, CT 06109; tel. 860-257-7635; www.barklayandeve.com). Each of the eight titles in this series examines a topic adults may find difficult to discuss with children, such as going to a funeral, understanding cremation, hospice, pet loss, and organ and tissue donation. There is room for a child to draw and color while learning lessons like: loss and sadness do happen; those events are not anyone's fault; it is OK to have strong feelings as long as they are expressed in constructive ways; and "we can get through anything with the love and support of family and friends" (Book 1, p. 5).

Fox, M. (1994). *Tough Boris*. New York: Harcourt Brace. Boris von der Borch is a huge, tough, scruffy, greedy, fearless, and scary pirate—just like all pirates. But when his parrot dies, Boris cries and cries—just like all pirates, and everyone else. A simple story and pictures give children permission to experience and express their grief.

Muñoz-Kiehne, M. (2000). *Since My Brother Died/Desde Que Murió Mi Hermano*. Omaha, NE: Centering Corporation. With text in both English and Spanish, a child wonders if a brother's death is only a dream or if anything could have been done to prevent his death. The child and his family are sad. Afraid of forgetting his brother, the child begins to paint—simple watercolor illustrations gradually turn into rainbows and the confidence that life can go forward.

Raschka, C. (2007). *The Purple Balloon*. New York: Schwartz & Wade. This book observes that children who draw their feelings when they become aware of their impending death often draw a blue or purple balloon, released and floating free. Here balloon images first depict the death of an elderly person before turning to a dying youngster. The text says, "Good help makes leaving easier" and offers suggestions for those who want to help make dying not so hard

Storybooks and Other Texts for Primary School Readers:

Adams, G. (2006). *Lessons from Lions: Using Children's Media to Teach about Grief and Mourning + CD*. Little Rock, AR: Center for Good Mourning, Arkansas Children's Hospital (800 Marshall Street, Slot 690, Little Rock, AR 72202). This booklet explains how to use 10 slides from Disney's *The Lion King* (1994) to encourage discussions about three unhelpful reactions following a loss: (1) running away from the problem, the pain, and those who love you; (2) pretending the bad thing never happened; and (3) never telling anyone about your feelings and experiences them. The positive lesson is: By not making any of these mistakes, we can keep the person with us in our hearts.

Bunting, E. (1999). *Rudi's Pond*. New York: Clarion. While Rudi is sick, his friend and classmates send cards and make a big "GET WELL RUDI" banner for his hospital room. After Rudi dies, the children write poems and make a memorial pond in the schoolyard that attracts a beautiful hummingbird.

Dickerson, J. G. (1995). *Grandpa's Berries: A Story to Help Children Understand Grief and Loss*. Johnstown, PA: Cherubic Press. On a visit to her grandparents, Alice tastes a wonderful, orange-gold raspberry. Later, after Grandpa has died, Alice discovers that the raspberry bush is also dead. As they share their grief, Alice's mother says she will never forget the special taste of those berries even though



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now they are gone. The same will be true for Grandpa: "The remembering will become easier until one day you'll notice that all that's left is the sweetness that you remember. Just like the berries."

Goldman, L. (2006). *Children Also Grieve: Talking About Death and Healing*. Philadelphia, PA: Jessica Kingsley Publishers. This book combines a story told by a dog named Henry and his questions to readers, a section for making a memory book, a two-page glossary of grief words, and advice for caring adults. Henry's story uses photographs and text to tell about the sadness following the death of Grandfather. He explains what death means, what grief is like, things to do when you are sad or scared, and ways to feel a bit better. Blank spaces allow readers to respond to questions.

Grollman, E., & Johnson, J. (2006). *A Complete Book About Death for Kids*. Omaha, NE: Centering Corporation. The three main parts of this book address death and feelings, funerals and cemeteries, and cremation, respectively. Most pages have photos and a few simple sentences directed to child readers and adults who might interact with those children.

Hemery, K. M. (2001). *The Healing Tree*. Omaha, NE: Centering Corporation. This story compares grief in a family to a tree struck by lightning. Just as the tree lost one of its main branches leaving only a bare strip on its trunk where there is no bark, Papa says that they are all in pain after Mama's death. But like the tree, Papa says they will heal and go on living, even though life will be different and forever changed.

McLaughlin, K. (2001). *The Memory Box*. Omaha, NE: Centering Corporation. A young boy is mad at Grandpa for dying when he had promised to take the boy fishing. Mommy agrees the boy will miss doing things with Grandpa, but she tells him to hold onto good memories of all they shared. One way to do that is to make a memory box and to put into it objects that help the boy remember this special relationship.

Peterkin, A. (1992). *What About Me?* Washington, DC: Magination Press. Laura and Tom are siblings who often play together and sometimes quarrel. One day Laura learns that Tom is sick and in the hospital. She misses Tom, feels responsible for his illness, and worries he might die. Their parents and other adults seem to focus only on Tom, while ignoring Laura's needs. Finally, Laura's parents and the doctor explain Tom's illness to her, let them play together, and take her out for a special treat.

Plourde, L. (2003). *Thank You, Grandpa*. New York: Dutton Children's Books. On their walks in the woods over the years, a girl and her grandfather share many discoveries. When they find a dead grasshopper, the girl asks, "What can we do?" Grandpa says: "We can say thank you and good-bye." Years later, as the girl walks alone, she says to herself: "Thank you, Grandpa, for our walks. You kept me steady when I wasn't so steady. You let me run ahead when I was ready to run ahead. . . . But most of all, thank you for teaching me the words I need to say. . . . Grandpa, I love you and I'll miss you. But I will never forget you. Thank you and good-bye."

Schwiebert, P., & DeKlyen, C. (1999). *Tear Soup: A Recipe for Healing after Loss*. Portland, OR: Grief Watch (2116 NE 18th Avenue, Portland, OR 97212; 503-284-7426; www.tearsoup.com). "An old and somewhat wise woman" called Grandy who has just suffered a big loss in her life fills a soup pot over and over again with her tears, feelings, memories, and misgivings. Rejecting foolish advice, *Tear Soup* affirms all of the feelings and experiences that bereaved persons encounter, while encouraging them as they cope with loss and grief.

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Items of Interest:

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

Reader's Corner

In this issue, we continue a new, occasional feature inaugurated in issue #13. The Reader's Corner 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 will 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 would 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.

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, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, and families experiencing transitions associated with pediatric palliative care. (Please note that you can access archived issues of this newsletter at nhpco.org/pediatrics.) For future issues, we are thinking about addressing subjects such as alternative therapies in pediatric palliative care and making memories or legacy building. 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!

Pediatric Palliative Care at the Clinical Team Conference

ChiPPS is proud to have created a Pediatric Intensive track that will be part of [NHPCO's 10th National Clinical Team Conference](#) held in Denver, CO, September 24 – 26, 2009. In addition, a preconference seminar, "Hope for the Best, Plan for the Worst: Decision-Making and Advance Care Planning for the Child with a Life-Limiting Condition," is being offered on September 23 at the CTC.

Submit a Conference Proposal for 2010 MLC

The call for session proposals for NHPCO's 25th Management and Leadership Conference in Washington, DC, April 22 - 24, 2010, is now open. A robust program of educational sessions is being sought that reflect the conference theme, *Securing Our Roots, Expanding Our Reach*. The call for proposals is open through **September 18, 2009** and will **not** be extended. Visit the [Call for Proposals](#) to learn about the areas of emphasis and topic suggestions for this important conference for managers and leaders.

Free Resources from Caring Connections

Caring Connections has resources that you can use directly with families caring for a seriously ill child or supporting a child dealing with grief. To view free downloadable versions of those documents and learn how to order bulk copies, visit caringinfo.org/pediatrics. Caring Connections also has a free pediatric outreach guide to help you strength community understanding about the needs of seriously ill children and their families. Download the free guide at caringinfo.org/community/pediatricoutreach.



Support Partnering for Children/Wear a Bracelet.

Partnering for Children is a national awareness campaign that was launched November 2007 at NHPCO's Clinical Team Conference. The goal of Partnering for Children is to help get the word out about compassionate, family-centered healthcare for children with life-threatening conditions. The ChiPPS work group and the resources ChiPPS makes available is an important part of this campaign. In the memory of the many children whose wisdom and courage inspire us, inspirational bracelets developed by [Children's Hospice and Palliative Care Coalition](#) are now available through Partnering for Children. These inspirational bracelets which bear poignant messages from children can be ordered directly online at partneringforchildren.org or by calling 1-800-646-6460. One hundred percent of the net proceeds of these bracelets go directly to improving care and quality of life for children with life-threatening conditions. For more information on the Partnering for Children campaign, including how to join as a campaign partner, please visit partneringforchildren.org.

Online Courses in Collaboration with the National Center for Death Education (NCDE).

NHPCO is proud to collaborate with the NCDE at Mt. Ida College in Newton, MA to provide ongoing educational programs for hospice and palliative care professionals and volunteers. There will soon be a series of courses specific to Pediatric Palliative Care. These online courses enable you to acquire and maintain a current knowledge base, as well as develop creative and useful skills for providing care associated with end of life, bereavement and loss. For more information about NCDE, visit mountida.edu/ncde or contact NCDE at 617/928-4649.

Calendar of Events.

As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, nhpco.org/pediatrics. Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

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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.

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