



E-NEWS

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and Mary Kay Tyler, RN, MSN, CNP*

Issue Topic: Pain and Pain Management in Pediatric Palliative Care

Welcome to the fourteenth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter continues the focus of issue #13 on pain and pain management in pediatric palliative care. Here you will find links to a PDF collection of articles on these topics that have been contributed by professional colleagues and family members. Please note that you can visit archived issues of this newsletter at www.nhpc.org/pediatrics. At that site, you can access both issue #13 and four important related articles by Dr. John M. Saroyan that appeared in issues #1, 2, 3, and 5 of our newsletter. Dr. Saroyan, sometimes writing with colleagues, contributed insightful articles on assessment and pharmacologic management of pediatric pain, touching on such topics as neuropathic pain and usage of methadone.

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 Mary Kay Tyler. 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 Mary Kay at mktyler@hospicewr.org.



Issue #14: Pain and Pain Management in Pediatric Palliative Care

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

Little Girl, Little Boy; Now Is the Time

p. 5

James Oleske, MD, MPH, FAAP

Dr. Oleske, professor of pediatrics and medical director of the Circle of Life Program in New Jersey shares one of his provocative poems with us.

A Mother's Wish: Meaningful Interventions for Pain Management

p. 6

Lisa Buell

Lisa, a frequent contributing author to our newsletter, again provides us with a thought-provoking piece from her perspective as a mother providing useful guidance for all healthcare professionals working with children facing life-threatening conditions and their families.

Neonatal Pain

p. 9

Suzanne S. Toce, MD

A neonatologist and leading expert in pediatric palliative care, Dr. Toce was instrumental in the development of Footprints© a program for neonatal palliative care. In this article, Dr. Toce provides an overview of neonatal pain and includes valuable reference materials.

Pediatric CAM Therapy with Emphasis on Palliative Care

p. 12

Joelle Mast, PhD, MD

There is a growing trend in the use of Complementary and Alternative Medicine (CAM), alongside traditional Western medicine. Dr. Mast provides an overview of the interaction between mind and body and the use of CAM. She provides a brief historical perspective and discusses different aspects of using CAM therapies such as communication, prevalence, professional liability, best practice and the use of CAM in the treatment of pain and symptom management.

The Social Work Role in Pain and Symptom Management with Children

p. 20

Cynthia Daughtry, MSW, LICSW, and Stacy Remke, MSW, LICSW

"The importance of effective, timely, and family-centered care to alleviate the pain and suffering of children with life-threatening conditions cannot be over-estimated," and caring for children effectively requires an interdisciplinary team. Cynthia and Stacy, members of the Children's Institute for Pain and Palliative Care Program at Children's Hospital in Minnesota provide the social work perspective.

Spiritual Suffering Scale: A Teaching Tool

p. 24

Bonnie Meyer, DMin

Offering relief for suffering in end-of-life care is at the core of good practice in pediatric palliative care. Various tools are used to achieve consistent and effective assessments of levels of suffering. Dr. Meyer has created a tool to assess spiritual suffering by providing a common ground for all to understand and to use in their efforts to ease spiritual suffering. (Note that this tool was originally designed to be used with adults; it will need to be adapted for use with children and adolescents.)

The International Children's Palliative Care Network (ICPCN) and its Charter of Rights for Children with Life Limiting and Life Threatening Illnesses

p. 25

We attach to this issue of our newsletter information about ICPCN and a copy of its Charter (first published in October 2008). **Sue Huff, RN, MSN, former Co-Chairperson of the ChiPPS Advisory Council, represents NHPCO and serves on the Steering Committee for ICPCN.** Sue is also a member of their quality and standards subcommittee and in addition to monthly conference calls contributes to their quarterly newsletter to report Palliative Care and Hospice News from the USA and Canada.



Readers' Corner

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Suzanne S. Toce, MD

Dr. Toce provides a helpful summary and comments on a recent article from the *American Journal of Hospice and Palliative Care OnlineFirst*

Items of Interest

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

1. Subjects and Contributors for Future Issues of This Newsletter
2. NBCHPN Pediatric Certification Exam Survey.
3. Upcoming Meeting
4. Pediatric Palliative Care at Clinical Team Conference
5. Online Pediatric Listserv
6. Calendar of Events

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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.



LITTLE GIRL, LITTLE BOY; NOW IS THE TIME

James M. Oleske, MD, MPH, FAAP
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Little girl, little boy, where are you going
Taken' away by a new plague?
Little boy, little girl, why are you so frail
Wastin' away from an OI?
Little girl, little boy, where are your folks
Called away by HIV/AIDS?
Little boy, little girl, why are you so sad
Left alone without a safe nest?

Frail and poor, vulnerable and weak,
An orphan, alone, with no one to care?

Little girl, little boy, why will you die
No medicine to treat this virus in you?
Little boy, little girl are you so small
That nobody worries what happens to you?
Little girl, little boy are you so lost-
That your name is unknown, on nobody's list?
Little boy, little girl have you only survived
As someone's tool or somebody's toy?

Lost and abandoned, without a safe home,
Why have so few come to your aid?

Little girl, little boy, some hear your cry
Bringing drugs to treat and food to eat.
Little boy, little girl, please stay alive-
Forgive us your suffering and untimely deaths!
Little girl, little boy, but are we too late
Your tiny hands hold our world's fate!
Little boy, little girl, wherever you live-
Need share in earth's resources for quality of life!

Children so frail, sad, poor, vulnerable and weak,
So small, lost, forgotten, abandoned and weak,
Need more than good wishes to live, grow and be well!

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A MOTHER'S WISH: MEANINGFUL INTERVENTIONS FOR PAIN MANAGEMENT

Lisa Buell

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Lisa is a parent advocate for
Partnership for Parents

As parents and family members of children with life-threatening or life-limiting illnesses, we are constantly weighing the pros and cons of interventions, the benefits vs. burdens. One of our biggest concerns is keeping our children pain free, despite knowing that we can't expect to live in a world without pain. Inevitably, there is going to be emotional and spiritual pain, and that will always be challenging. Still, with modern medical technology, we need to know that our child's physical pain will be managed effectively.

When my daughter Madison was diagnosed, I was desperate for a doctor to sit with my family and me and tell us that Maddy's pain was the first priority. It's been ten years since my daughter took her last breath; I know there have been many changes in that time within the medical institutions. Here is a wish list of sorts; some came true for us, while others did not. What follows is a combination of both. I realize now, after training with the Initiative for Pediatric Palliative Care, collaborating with Children's Hospice and Palliative Care Coalition, and the insights gained through conversations with clinicians that there is a difference between pain and suffering. Pain must be managed in order for suffering to be nonexistent; unmanaged pain decreases the quality of life and creates memories that last well past a lifetime, affecting generations of families. As clinicians you have chosen an incredibly challenging but rewarding field. My hope is that this wish list will help increase your job satisfaction and help to ease your suffering.

We need to have a conversation, I need assurances that my child will not be in physical pain under your care. I want to hear the words come directly from the doctor's mouth. In effect, I want to shake on it and seal it with blood.

We have to talk about the different types of pain management and how they may impact my child's cognition, affect, and interaction with the rest of our family. It's important for me to see not only the map of care but also the territory of what lies ahead. I need to be trained on how to manage my child's pain so we can have a life outside the hospital. I need to know that there are support people I can call day or night if my child is hurting, people who will give me the tools to work through it. I want to know why it's important to follow the pain protocol instead of feeling proud that my child doesn't need to take as much pain medication as is recommended. I need to be presented with not just the treatment options, but also what can happen if we decide to pursue the treatment, as well as what could happen if we don't. And, I want help understanding the differences between treatments of pain and recreational drug use.

I long for a medical team that can sit and listen to my concerns, even when they may sound irrational. It scares and confuses me when you look at your watches or shift in your seats. I want clinicians to give me their full attention, empathy, and understanding, and let me know that you are going to do your very best. Tell me that managing my child's pain is one of your highest priorities. That you will continue to talk with me about pain and symptom management throughout my child's care. You have to empower **me**, the parent, by acknowledging that I am one of the most reliable and greatest gauges of my child's pain because I know my child the best. I need to know that you will be monitoring my child regularly and looking to me for guidance.



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Help me by showing empathy and understanding around the enormity of having to make decisions for my child that no parent should ever have to make—and support me in having compassion for myself as I make them.

There will come a day when clinicians can inform parents about homeopathic interventions that we can use in conjunction with the clinical interventions, like using lavender for nausea, or Reiki for managing fever and reducing stress. I need for you to appreciate the mystery of medicine and inform me about interventions that have worked for other families. I want the eye rolling to stop and the understanding to happen. We are compelled to do the best for our children and sometimes that might include alternatives to Western medicine.

Help me to understand the importance of looking at our children and family as a whole, provide me with a list of resources, and personally introduce the other members of the team... Stress the importance of building a relationship with all the other members of the palliative care team. Know that my child is broken and with each passing minute I am breaking too; the world is spinning so fast and I need for someone to help me make it stop. I need to understand that we are all working together or else I will end up being the parent who wants the doctor or surgeon to fix my child. I have yet to understand how challenging our lives are going to be and that I will need this tribe of professionals to help me and my child navigate the waters of procedures and protocols.

Tell me about the art therapy center, and invited me participate with my child. If you don't have one, offer me some paper and crayons. If my child dies, I want someone to dedicate an art program in her honor, or give art supplies to a school in my child's name so she may live on. I need for clinicians to acknowledge my child's life by writing a card, talking with me personally after she died, coming to the service, planting a tree, climbing onto a hilltop and saying the names of all the children who have died. It's such a gift to hear our children's names, have people share their memories and tears with us...depending on the relationship we have built with you.

Know that your medical expertise will be fully revealed only when you are able to demonstrate your cultural competence. That can only be obtained by your willingness to dip into your heart and have the courage to show your empathy and understanding in ways that are meaningful to our family.

What if clinicians could walk into the room with some practical help or advice instead of asking me how I am feeling? How do people think I feel when my child is seriously ill and my life has come unglued? Instead, ask what I've been thinking about, or tell me you've been thinking about us. Or give me the code to the rooftop garden so I can be with my fears surrounded by a pinch of nature. Sometimes a fist full of chocolate and the National Enquirer can be the best medicine.

I wish every hospital had a resource binder describing pediatric palliative care and each family was given one at the same time we received our child's diagnosis. So that after I have gotten my treatment options, been told about the wealth of resources available, and talked about the process of decision making and protocols, I would walk away with a binder that describes that initial conversation in more detail. In a sense, you would be providing me with a touchstone to keep with me and consult from time to time. I also want to have the other binder as well, the one that talks about when our child is dying. Give that to me during our difficult conversation so that my family will have a plenty of time to learn how to live while my child is dying.

I wish for the same quality care when my child is fighting the disease as when the options for curative treatment aren't as viable. You are professionally and morally obligated to give me a list of options, ask me how I want to spend the last months, and help to come up with an end-of-life plan of care. My wish is that the cushion of care that surrounded me will not immediately be ripped away once my child has died.



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I want the clinicians to talk, share information, and look at the notes before asking a question that I have already answered four other times that day. I need for the nurses and the doctors to be in agreement about the plan of care from the general to the specific because I am scared to death and can't afford to hear inconsistent information. I want you to have taken the time to come into my room prepared and ready to work and expect me to do the same.

I want a professional whose sole job it is to advocate for me, help me organize my child's care at home and in the hospital, help me with the mounds of paperwork, and help me to remember what the doctors told me. I want that person to guide me as I try to jump through the various hoops within the medical system and navigate the unavoidable complexities of the bureaucracy. This professional would be responsible for knowing what members of the team are doing and be able to explain their roles to me. I want a professional who is competent to evaluate my child's care, ensuring that everything that can be done is being done.

Tell me about how other families are caring for their children at home, share their tricks and hard won wisdom with me. I want to know that I can keep my child safe. I want to be encouraged to take notes and ask questions. Provide me with opportunities to meet and talk with other parents.

Please see my child as a whole and help me to keep that perspective as well. I want the clinician with whom I have a relationship to deliver both the good news and the bad.

Share your insights about hope and tell me it cannot be created or destroyed, that it isn't dependant upon results. Let me know that sometimes hope can change. Give me friendly care, not a clinician who wants to be a friend. You must have the courage to step in and say what needs to be said, even if it's upsetting. It's such a gift when a clinician can be comfortable within the uncomfortable.

Make your mental and physical health a priority; tell me how you manage your stress, so it can give me permission to do the same. I want to look at the insurmountable hill of caring for my seriously ill child, see the dirt in your shoes and the flag in your hand. Show me your humanity and make room in your heart for mine, because we are in this together. Tell me I am doing a great job and accept the compliment when I tell you the same. If that's not the case, we have to be able to talk about that as well.

I want my child to live a healthy and productive life. If that doesn't happen, I have to know that everyone did his or her very best or I will suffer and not be able to grieve properly.

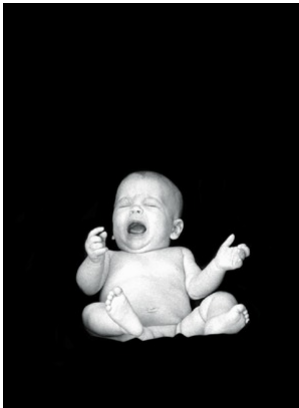
Please know how thankful and grateful we are to you for sharing your gifts with us, even if we don't say it out loud. Often words can't possibly convey the kind of gratitude we hold in our hearts and sometimes we don't realize how we really feel until years later when the dust has settled. We thank you for your courage, for your hearts, and for running into the fire instead of away from it.

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NEONATAL PAIN

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“Pain is inevitable: Suffering is optional.”

Anonymous

It is clear that newborns experience pain. Pain results in physiologic, metabolic, and behavioral changes. Untreated, severe, or prolonged pain increases mortality and morbidity. Why do healthcare providers ever perform painful procedures without providing analgesia? When queried about circumcision, those physicians not providing analgesia cited concern over risks of analgesia, perceptions that analgesia isn't warranted or is ineffective, unfamiliarity with the techniques, and time constraints.

What is the scope of the problem?

- Healthy term newborns have 3-5 painful procedures in the nursery
- In the NICU, each newborn has an average of 16 painful or stressful procedures per day, almost ¼ without pharmacologic or nonpharmacologic therapy

What does research teach us about neonatal pain?

- Pain in newborns is frequently unrecognized and undertreated
- Newborns, even premature newborns, are capable of feeling pain
- Newborns are no less sensitive to pain than older children; in fact they may be more sensitive and more susceptible to long-term effects
- Newborns are capable of expressing pain and discomfort
- Newborns do not need to learn about pain; they can feel it with the first experience
- Newborns do remember pain, especially repeated noxious stimuli
- Neonatal pain has short and long-term adverse effects
- Pain can be accurately assessed at the bedside with validated tools
- Pharmacologic and non-pharmacologic measures to provide pain relief are available and safe

What are the procedures that elicit a “pain response?” Some obvious ones include surgery, blood drawing, peripheral IV insertion, circumcision, immunizations, and chest tube placement. However suctioning, NG tube insertion, intubation and extubation, eye exams, LP, position changes, IV medication



infusion, and withdrawing blood from catheters all can elicit behavioral and biochemical responses indistinguishable from pain responses.

How can caregivers assess pain? Newborns manifest pain by behavioral means such as crying and changing facial expression, as well as physiologically by changing vital signs or oxygen saturation. However, a lack of behavioral response does not mean the newborn is not in pain. There are several acute pain scales that have proved useful in assessing pain in the term and preterm neonate. Scales used in the NICU include CRIES (Crying, Requires increase FiO₂, Increased vital signs, Expression, and Sleeplessness), NPASS (Neonatal Pain, Agitation and Sedation Scale), and PIPP (Premature Infant Pain Profile). NIPS (Neonatal Infant Pain Scale), the Modified Infant Pain Scale, and NFCS (Neonatal Facial Coding System) can be used both in the well baby nursery and the NICU. Not all of these have been validated in premature infants. NPASS and PIPP specifically adjust the scale based on prematurity. Use of one of these pain scales should be incorporated into routine assessment of all babies including those in the well baby nursery. By assessing pain during and after procedures as well as with treatment, specific therapy can be swift and appropriate. Caregivers can also learn the benefits of prophylactic treatment for painful procedures.

What nonpharmacologic and pharmacologic tools are available to safely manage neonatal pain?

In general, preventing, limiting, and clustering painful stimuli are options for reducing the negative effects associated with neonatal pain. An international consensus statement of appropriate non-pharmacologic and pharmacologic analgesic interventions has been published (see attached table "Suggested Management Approaches"). Non-pharmacologic interventions such as swaddling, positioning, non-nutritive sucking, and holding with skin-to-skin contact are beneficial for mild discomfort. Oral sucrose may modify mild pain and can be incorporated into standing orders for use with heel lance and injections in the well baby nursery and NICU. Noxious environmental stimuli result in behaviors indistinguishable from pain responses, and may result in similar morbidity. Therefore, minimizing noise, light, and other negative stimuli should be a goal in the NICU.

When avoidance is not possible, appropriate analgesia must be provided. Healthcare providers must understand the unique dosing and safety issues of available analgesic drugs. Cardiorespiratory monitoring of the newborn and availability of trained staff may be needed. Procedural pain for bedside procedures such as chest tube insertion can usually be managed by infiltration with local anesthetics such as lidocaine with or without systemic analgesics. In some cases LMX-4 or Lidocaine-prilocaine 5% (EMLA) can be safely applied topically in advance of procedures such as lumbar puncture, venepuncture, circumcision, and peripheral intravascular catheter placement. Unfortunately, these topical lidocaine creams do not reliably eliminate pain associated with heel-lance procedures and EMLA has the slight risk of methemoglobinemia. As use of an indwelling catheter or venepuncture is less painful than heel-lance, these alternatives should be considered where appropriate.

The limited data available suggest that nonsteroidal anti-inflammatory drugs and acetaminophen may be helpful for mild to moderate pain and as an adjunct to opioid medications. Data on ibuprofen in the neonate are limited.

Opioids are effective for moderate to severe pain such as bedside procedures (i.e., chest tube placement), surgery, post procedural pain, and for medical conditions that are painful, such as necrotizing enterocolitis. Pharmacokinetics in the newborn, and especially the premature newborn, are different than in older infants and therefore require attention to dose and interval. Opioids are generally given orally and by intermittent or continuous intravenous infusion. Continuous infusions result in fewer variations in drug levels and may be preferred if long-term use is necessary. Inappropriate fears of addiction, tolerance, dependence, and adverse effects such as respiratory depression (incidence probably less than 1%) may contribute to inadequate dosing. *These issues are indications for monitoring, vigilance, and availability of skilled personnel, not withholding appropriate medication.*



In summary, pain in the newborn is under recognized and under treated. Any procedure considered to be painful in an adult should be considered to be painful in a neonate and treated accordingly. Appropriate treatment of pain has been shown to be associated with reduced mortality and morbidity. Bedside assessment of pain is facilitated by the routine use of neonatal pain assessment tools. Both pharmacologic and non-pharmacologic measures should be used as appropriate to manage pain. Healthcare professionals have the responsibility to treat the pain of their newborn patients. Written policies, guidelines, and standing orders can facilitate this treatment.

*"How sweet for those faring badly to forget
their misfortunes for even a short time."*

- Sophocles

Resources:

- American Academy of Pediatrics Committee on Fetus and Newborn and Fetus and Newborn. Prevention and management of pain in the neonate: An update. *Pediatrics* 2006;118:2231-2241
- Anand KJ. Consensus statement for the prevention and management of pain in the newborn. *Arch Pediatr Adolesc Med.* 2001 Feb;155(2):173-80
- Buchholz M, Karl HW, Pomietto M, et al. Pain scores in infants: A modified infant pain scale vs. visual analogue. *J Pain Management* 1998;15:117
- Carbajal R, et al. Epidemiology and treatment of painful procedures in neonates in intensive care units. *JAMA* 2008;300:60-70
- Krechel S, Bildner J. CRIES: A new neonatal pain measurement score. Initial testing of validity and reliability. *Pediatr Anesth* 1995;5:53-61
- Lawrence J, Alcock D, McGrath P, et al. The development of a tool to assess neonatal pain. *Neonatal Network* 1993;12:59-66
- Lynn AM, Ulma GA, Spieker M. Pain control for very young infants. *Contemp Pediatr* 1999;16:39-66
- Royal Australasian College of Physicians: Management of Procedure-related Pain in Neonates, 2005 <http://www.racp.edu.au/page/health-policy-and-advocacy/paediatrics-and-child-health> (accessed 8/5/08)
- Stevens B, Johnston C, Petryshen P, Taddio A. Premature infant pain profile: development and initial validation. *Clin J Pain* 1996;12:13-22

Appendix

A number of tools are available that are helpful and will be of interest to readers. Due to copyright regulations, ChiPPS cannot provide the scales and table, however, citations for these resources are provided.

1. Modified Infant Pain Score Scale.

From Buchholz M, Karl HW, Pomietto M, et al. Pain scores in infants: A modified infant pain scale vs. visual analogue. *J Pain Management* 1998;15:117.

2. Neonatal Infant Pain Scale (NIPS).

From Lawrence J, Alcock D, McGrath P, et al. The development of a tool to assess neonatal pain. *Neonatal Netw* 1993;12:59-66.



3. Neonatal Facial Coding System (NFCS).

From Grunau RVE, Craig KD. Facial activity as a measure of neonatal pain expression. In: Tyler DC, Krane EF, eds. *Advances in Pain Research Therapy*. New York, NY: Raven press;1990:147-154. *Pediatric Pain*, vol 15.

4. N-PASS: Neonatal Pain, Agitation, & Sedation Scale.

From Hummel P, Puchalski M, Creech SD, et al. Clinical reliability and validity of the N-PASS: neonatal pain, agitation and sedation scale with prolonged pain. *J Perinatology* 2008; 28:55-60. [Chart available at www.n-pass.com/assessment_table.html, 02/26/09.]

5. Premature Infant Pain Profile.

From Stevens B et al. *Clinical Journal of Pain* 1996;12(1):13-22.

6. Neonatal Pain Medications

Pediatric Dosage Handbook with International Trade Names Index: Including Neonatal Dosing, Drug Administration, & Extemporaneous Preparations. Taketomo CK, Hodding JH, Kraus DM. 2006, Lexi-Comp Inc.

7. Suggested Management Approaches.

From Anand et. al. Consensus statement for the prevention and management of pain in the newborn. *Arch Pediatr Adolesc Med* 2001;155:173-180.

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PEDIATRIC CAM THERAPY WITH EMPHASIS ON PALLIATIVE CARE

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Definitions

Health

According to the World Health Organization¹, health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. This definition has not been amended in the past 60 years. Complementary medicine refers to health practices used alongside traditional western medicine. Alternative medicine generally refers to interventions that are used instead of traditional medicine. The term integrative medicine indicates the use of both conventional and CAM therapies that have some demonstrated efficacy. Some feel that this integrated approach helps redirect the focus from healing to the holistic concept of health as defined by WHO.

CAM Therapy

In this article, we will use the term CAM therapy as defined by the Institute of Medicine²

"Complementary and Alternative Medicine (CAM) is a broad domain of resources that encompasses health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the dominant health system of a particular society or culture in a given historical period. CAM includes such resources perceived by their users as associated with positive health outcomes. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed."

The National Center for Complementary and Alternative Medicine³ provides a similar definition and classifies complementary and alternative therapies into five overlapping groups:

1. Whole medical systems such as homeopathy, Ayurveda, or Traditional Chinese Medicine (TCM).
2. Mind-body medicine concentrating on the complex interactions among interconnections of mind, body, and spirit. Examples include meditation and relaxation.
3. Biologically based practices using herbs, foods, vitamins, and other natural substances.
4. Manipulative and body-based such as chiropractic.
5. Energy medicine using putative and verifiable energy fields such as Reiki or magnetic therapy.

The IOM report mentioned above states that all forms of therapy whether conventional or CAM need to be held to the same high standard of demonstrating clinical efficacy and that incentives be made available for necessary research.

CAM therapy gained such a large following in healthcare interventions that The White House commissioned a report on Complimentary and Alternative Medicine that was released in 2002⁴. This report supported a holistic orientation to healthcare delivery with an emphasis on health promotion and self care. It called for studies to provide evidence of safety and efficacy of CAM therapies. However, the



healing capacity of the person and respect for individuality was emphasized. The report reiterated the right of the individual to choose treatment. Importantly, partnerships across disciplines were felt to be essential to integrated healthcare. Education was felt to be a fundamental healthcare service. Therefore, dissemination of knowledge is imperative. Finally, the need for the public to play an active role was emphasized.

Interaction between Mind and Body:

There is a complex interaction between the mind and the body. Spirituality is recognized as a factor in healing; meditation has well documented physiological effects.

A large number of CAM therapies are based on the interaction between mind and body. Examples include therapeutic touch, relaxation, guided imagery, and meditation. Brain activity is influenced by emotions. Our thoughts and feelings influence the production and regulation of neuronal transmitters, neuropeptides, immunomodulators and hormones. In turn our brain activity patterns influence emotion and sensory perception. Exercise is an example of this. Exercise including aerobic, interval and weight training has been associated with decreased pain, increased energy and elevation of mood.⁵ Emotions also play a role in stress responses and immunocompetence. Psychoneuroimmunology is a relatively new field that offers promise and understanding of how various complementary modalities interact with the immune system.⁶ The recent evidence that the brain is capable of making changes and adapting to its environment throughout the lifespan gives us hope that the physiology underlying mind/body may be elucidated further.

Some apparently simple and obvious CAM therapies offer insight into the complexity of the mind body interaction. One example of this is music therapy, and entrainment. A classic study by Rider⁷ found that the most effective type of music therapy in management of pain was not what we would think of as relaxing but rather music that moved from a faster, somewhat "tenser" 7/8 meter to a slower 4/4 meter. The tense mood of the patient must first be captured and then brought down by bringing the music down. A loose analogy is found in visual evoked potentials. The stimulus frequency that is captured by the brain when the subject is in a relaxed state is one that matched the resting occipital frequency, not one that is slower. Various meta-analyses have demonstrated the usefulness of music therapy in patients ranging from adult⁸ to infant.⁹

Other CAM therapies illustrate the variation in responses across individuals. For example, essential oils are used for stress and anxiety, chronic pain, depression, and insomnia. Lavender is claimed to be calming; rosemary and peppermint to be stimulating. However, just as taste and nausea are linked so that strong associations are easily formed, so too odors are easily linked to memories associated with the odor. Like or dislike of a smell affects the physiological response rather than something inherent in the stimulus itself. Randomized controlled trials (RTCs) are lacking and in a pediatric population there are concerns about accidental ingestion and about sensitization leading to allergy. Most essential oils are lipid soluble and absorbed through skin. This absorption can be increased with rubbing so that massage with essential oil may be unwise in a small infant. Patch testing is recommended before use.

Prevalence

The use of CAM therapies, while varying with country and ethnic groups, is widespread. Nearly three quarters of US adults surveyed reported having used CAM therapy within the past year.¹⁰ Excluding prayer from CAM therapies yielded a figure of 36% use by adults within the past year. Some commonly used complementary or alternative therapies are listed in Table 1. Some have been practiced for



thousands of years and have a broad cultural and religious base without an identified founder; others are the product of an individual theory of health (e.g. chiropractic medicine, homeopathy).

A self-administered questionnaire to parents of children in a university hospital outpatient clinic found that 11% had consulted practitioners of alternative medicine including: chiropractic medicine, homeopathy, naturopathy, and acupuncture. Parents of children who used CAM therapy had an increased incidence of CAM therapy use themselves. Use of CAM therapy was greater in older children.¹¹

Parent/Practitioner Communication

Data from the 1996 Medical Expenditure Panel Survey found that 2% of pediatric visits were to CAM providers. Interestingly, only 12.3% told their primary care practitioner about these visits. Most common providers of CAM therapy were chiropractic and spiritualists. Herbal remedies and spiritual healing were the primary modalities of treatment. Parental use of CAM therapy was the largest positive predictive factor in pediatric use of CAM therapy. Parental dissatisfaction with traditional care was a reason for seeking CAM therapy.¹²

When members of the American Academy of Pediatrics (AAP) were surveyed, 87% indicated that they had been asked about CAM by a patient or parent in the immediately preceding three months. Although over a third of these practitioners or a close family member had used CAM therapy, most were uncomfortable discussing it with patients. Over 80% wanted additional information about CAM therapy especially about nutritional therapy, dietary supplements, and therapeutic exercise. The majority of pediatricians felt that all potential therapies should be considered when treating patients.¹³ However, before endorsing a CAM therapy, practitioners must be aware of best practices to avoid patient harm and physician liability.

Professional Liability and Best Practice

In general, courts support parental decision-making because, correctly, parents are viewed as having their child's best interest at heart. However, there is great variability from state to state in the licensing requirements for practitioners of CAM therapies. In addition, the lack of RCTs especially with certain CAM therapies place primary care practitioners at risk when including them in the overall care plan. Without adequate knowledge, there is the potential of direct harm (e.g., liver damage or neuropathy), costs of lost opportunities, and indirect harm in terms of unwarranted financial or emotional burden.¹⁴

The American Academy of Pediatrics has issued a policy statement on counseling parents who are considering CAM therapy.¹⁵ Cohen and Kemper¹⁴ provide a decision-making framework within which a caregiver can operate. Following the mandate of *Primum Non Nocere*, questions to be considered include:

1. Would effective care be abandoned?
2. Is the child's condition potentially life limiting?
3. What risks are known for the CAM therapies under consideration? Can one develop an educated risk/benefit ratio that incorporates scientific fact and family desire?
4. Did all legal guardians consent and the child assent to the CAM therapy?
5. Is there a modicum of support for the proposed therapy in the literature?

In terms of ethics, for a child at end of life or with a life-limiting condition, it is reasonable and also more common practice, to support CAM therapies that may enhance the quality of life for the child and family.



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In these situations, parents' wishes, as well as the child's, take precedence over the absence of evidence of medical neglect or known harm from the CAM intervention.

We know that families will turn to CAM therapy and that over 50% will not inform the physician. Healthcare professionals need to ask about specific CAM therapies in language that parents will understand such as vitamins, dietary supplements, herbal treatments, in order to inform parents about possible interactions with medical treatments or known harmful effects. As with any treatment, it is incumbent upon the healthcare provider to monitor the literature for reports of adverse effects, and to monitor individual patients for side effects, whether or not the CAM therapy was endorsed. If endorsed, the physician should become familiar with the credentials of the CAM therapy provider, maintain lines of communication with parents and all who are providing services to the child, and have the medical record accurately reflect the child's integrative health plan and the physician's efforts.

Randomized Controlled Trials of CAM in Pediatrics

In keeping with the recommendations of the IOM and the White House Report on Complementary and Alternative Medicine, rigorous evaluation of CAM therapies is needed to increase our knowledge base and to avoid any unforeseen harm to patients. In the western world, evidence based medicine is held as the "gold standard." Randomized controlled trials (RCTs) enable us to check for internal validity of results and lack of bias. The ability to conduct RCTs varies with the specific CAM therapy. Clearly, it is easier to conduct such trials with biologic interventions compared to energy fields or prayer. There are fewer RCTs studies of CAM therapy in children than in adults, however, pediatric CAM therapy is common and RCTs are steadily growing. Most of these were reported in *The American Journal of Clinical Nutrition*, *Journal of Pediatrics*, *Pediatrics*, and *Lancet*. Over 90% were published in English with the next largest grouping being found in the Chinese literature. Medline indexed more of these articles than other databases investigated, with Medline identifying 97.7% of articles.¹⁶

To cut through the morass of reports in the CAM literature it is imperative that we apply uniform standards to available data. A rating scale by which RCTs could be evaluated was developed by Jadad.¹⁷ Using this scale, a survey of 251 CAM studies using RCTs found that over 80% of the studies were deficient in blinding of experimental groups and reporting of adverse events.¹⁸ Because these studies are difficult to conduct, especially in areas that are hard to quantify, it is important that Congress support collaborative projects that are designed by a multi-disciplinary team of pediatric experts representing the range of treatments and points of view.

Pain Management

CAM therapy in the pediatric patient is most often found in pain management, both acute and chronic, and in the setting of palliative care. Pain has been defined as "an unpleasant sensory and emotional experience arising from actual or potential tissue damage or described in terms of such damage."¹⁹ Because pain is subjective and highly individual, specialists in pain management have come to the consensus that pain is whatever the experiencing person says it is. Treatment of pain begins with the patient's experience. It is widely recognized that pain and suffering are greatly influenced not only by physiological factors but also by variables such as environmental factors, culture, and previous experience with pain. The goal of pain management is to enhance comfort, satisfaction, health, and survival. The tenets of pain management lend themselves readily to acceptance of CAM therapy.

Believing that unrelieved pain has adverse effects upon health and limits the child's ability to progress functionally, pain teams usually consist of specialists in a wide variety of disciplines and embrace



adjunctive therapies that may maximize relief. Because cultural and religious beliefs interact with pain and its expression, the family plays a large role in the care of their child and can provide invaluable information in assisting healthcare professionals in their assessment and management of the child's pain.

A Caveat: Complex Regional Pain Syndromes

Complex regional pain syndromes are difficult to treat. Here traditional opiate analgesia may fail abysmally, yet a careful protocol of intensive physical therapy, concentration on functional gains, and resuming age-appropriate activities is highly effective. One of the largest programs for children is that run by David Sherry MD at CHOP.²⁰ Pain is not emphasized and therefore, unlike [in] other types of pain [management programs], not measured at regular intervals. Rather, progress is measured by functional gains. The interdisciplinary team consists of an MD, PT, OT, music therapist, psychologist, education coordinator, case manager, and social worker. In addition to strength training, desensitization is used to decrease allodynia. There is an emphasis on making the child, rather than the parent, responsible for adherence to the plan. Relief of pain follows increase in function. Because of this, it is important to reassure the child that the therapy (i.e., strength training) will not cause harm and to establish trust between child and team members. We have followed a very similar program at Blythedale Children's Hospital for over 12 years with similarly high success rates²¹.

CAM Therapy in Pediatric Palliative Care

The incidence of pain in children with life limiting illness is especially high with a prevalence estimated at 1 in 1000.²² It is therefore not surprisingly that CAM therapies have been most commonly studied in the setting of palliative care. The American Academy of Hospice and Palliative Medicine provides this definition of palliative care: "The term palliative care ...now refers to the care of patients with life-limiting illnesses, whether or not they are imminently dying." The AAHPM states that:

*The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients facing life-threatening or debilitating illness and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care.*²³

Children, especially those with life limiting illness, may not be able to express their pain verbally. In addition, the heightened arousal common in a strange environment, or in the presence of fearful stimuli are known to increase perception of pain/suffering. CAM therapy in addition to direct effects on pain can lower the child's and the caregiver's anxiety. This underscores the need for practitioners of traditional medicine to see CAM therapies as enhancing the armamentarium we possess in order to minimize suffering and maximize quality of life. It is important to provide clinicians, families and patients with continuing education on cultural influences on and new modalities for pain management.

In pediatric hematology/oncology, up to 84% of patients have received some form of CAM therapy with or without the knowledge of their medical caregiver.²⁴ The modality most frequently seen is use of herbs for both the short term side effects of traditional cancer treatment such as nausea and vomiting, as well as for late effects of treatment such as fatigue and obesity. Unfortunately, the strength and purity of herbs varies and herbal products from other countries may be contaminated with toxins such as lead or microbial organisms. The latter is especially concerning in an immuno-compromised population.

Need for Individualized Treatment Plans



At Blythedale Children's Hospital we describe our care as child centered, family focused, and interdisciplinary. All care is individualized. It is important to remember that just as one person may have an idiosyncratic response to an oral pain medication, so too CAM therapies vary in their appropriateness for a child of a particular developmental level and in their efficacy among individual children at that level. Arrival at a truly individualized care plan requires a respectful, multidisciplinary collaboration with good communication. Unlike the siloed approach of old with each specialist contributing their piece, there is an understanding of the fact that a number of specialties may contribute to a particular functional domain and that a single specialty may contribute to many domains. Training in various forms of CAM therapy and allowing resources to be used based upon proper training but not on title is resource efficient.

Biofeedback may be used by therapists, psychiatrists, psychologists, and child life specialists. Therapeutic touch may be given by a nurse, therapist, or other practitioner. Medical play, guided imagery, and art may be used by child life and by psychology for different purposes each contributing to the integrated care of the child.

Overview

Despite problems regarding the strength and purity of herbal products and the fact that RCTs in the pediatric population are behind relative to the adult population, certain CAM therapies have become common enough to enable a practitioner to make some judgments about risk versus benefit ratio. A nonexhaustive list of CAM therapies which have published studies suggesting efficacy are: acupuncture for pain and nausea,^{15,25,26} valerian for insomnia,²⁷ Traumeel for mucositis,²⁸ hypnosis for anxiety and insomnia,^{29,30} biofeedback for pain.³¹ Ladas presents an overview CAM therapies used in children with cancer.²⁴ *Complementary and Alternative Medicine (2004)* while not pediatric in focus discusses the theory and evidence for a broad range of CAM therapies.³²

Given the limited resources available for healthcare, as well as the large burden faced by patients with complex chronic medical and other life limiting conditions, it is imperative that a cooperative effort be undertaken to assess outcomes and the cost/benefits of CAM therapies and their role in providing an integrative approach to care of these patients.

In summary, CAM therapy offers promise of expanding treatment interventions for the healthcare of pediatric patients. While RCTs are needed, the broader view of health espoused so long ago by WHO is being taken by ever increasing numbers of practitioners, patients, and their families.

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* * *

Table 1. Common CAM Therapies

Hypnosis	Chiropractic
Biofeedback	Acupuncture
Guided Imagery	Homeopathy
Massage	Aromatherapy
Herbs	Diet
Exercise	Therapeutic Touch

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THE SOCIAL WORK ROLE IN PAIN AND SYMPTOM MANAGEMENT WITH CHILDREN

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The importance of effective, timely, and family centered care to alleviate the pain and suffering of children with life-threatening conditions cannot be over-estimated. In a child with serious illness, the family's experience of pain is often like that of a crisis situation: usual coping strategies and behaviors are not effective in the face of unremitting pain. The perceived meaning of escalating pain can be an added burden to the family's resources for responding to the crisis at hand. Much attention has been directed at effective pain management strategies for children, including pharmacological intervention, integrative and alternative modalities, and psycho-spiritual support. However, the role of the social worker as a member of the interdisciplinary team charged with pain management has only recently been a topic for discussion amongst the social worker profession.

As a member of the hospice or palliative care team, the social worker is in a unique position to address the emotional, psychological, and social needs of the patient and family at the site where care is delivered, whether that is in the hospital or home setting. As a mental health generalist, the social worker can help bring theory and knowledge into the care setting, making this information useful in a way that amplifies strengths and identifies areas where support is needed to shore up family competence and coping. In pediatric palliative care, the family is the unit of care. Children are dependent upon their family's successful coping in order for their own well being to be assured. Effective pediatric palliative care requires sophisticated system analysis and intervention as often times many players become involved with these children's care.

Social workers traditionally bring knowledge regarding family systems dynamics, interpersonal relationships, and child and family development to the team. They also frequently become experts in the social service community within their area, so can quickly identify and refer families to resources that may be of assistance to them. In fact, this last area is one that is frequently the reason for referrals to social work. However, there is much more that the capable social worker can offer.

There is also a lesser-known role that social work often plays that revolves around tasks of advocacy and empowerment of the family within the healthcare system itself. By getting to know the family, how they function best, and what their identified needs are, the social worker is in a position to interpret these to the healthcare team, and also interpret the needs and activities of the healthcare system back to the family. When pressures on coping are high, challenges to managing the demands of complex care and decision making also rise. The social worker on the team can help families and teams negotiate a better "fit" between their needs, agendas, priorities, and communication styles.

When the pressure is on, the potential for strong feelings and a sense of urgency can increase. This can complicate communication efforts and lead to confusion. The social worker can take the time necessary to investigate family concerns and assist families in delivering important messages to the team. In issues related to pain, sometimes families have not identified issues that can be treated or addressed, and so may not recognize when to bring a symptom, like nausea or fatigue, to the attention of their child's physician.



At other times, parents may be reluctant to escalate pharmacologic interventions for a variety of reasons. By taking the time to discuss the “disconnect” between the team’s view of what is needed and the family’s concerns, points for education, clarification, and consensus can be identified. In situations where communications between the team and family have broken down, the social worker has training and expertise to assess the problem, and assist the team and family in developing a shared approach to problem definitions, problem solving efforts, and identification of the goals of care. In this way, expectations and needs can be interpreted across the cultural barriers that exist between the family system and the healthcare system.

In one example of this situation, a Hmong family was caring for a critically ill child. The doctors were very concerned because the parents agreed to the medication treatment plan but the family took the child home, did not give the medication to the child, passively avoided the palliative care nurses by not responding to phone messages to set up appointments, and did not answer the door.

The child was hospitalized again with a pain crisis. The social worker met with the parents and asked who the head of the family is. They said that it was the paternal grandmother. During the last hospitalization there had been a meeting between the doctors and the “family” in which the grandmother literally was not given a seat at the table and was left standing by the door. She felt disrespected and left the room angry. When the child was discharged the first time, the grandmother forbade the parents from accepting palliative care nurse visits and medications. She used traditional medicines from Asia. The social worker addressed the insult to the grandmother and helped to mediate the conflict between the grandmother and the doctors caring for the child.

The childhood game “connect the dots” provides an apt metaphor for this often painstaking and time-consuming task of communication. These efforts are often unfolding in the background of medical care provision, but are essential to effective intervention in a child’s pain. While an essential role for effective team functioning, it is often unconsciously addressed, with various members of the healthcare team and family attempting to address issues in a fragmented fashion.

More directly, the social worker is in a position to provide consultation and counseling to the family as needs arise, allowing timely intervention in a direct and expedient way. For example, when families worry about addiction with increased opioid doses, how to discuss difficult subjects with their 7 year old, or how escalating pain may mean death is approaching, social workers have the diverse skill sets that enable them to intervene wherever the family is focused. While other members of the team also have these discussions with families, the social worker’s unique ability is to address a variety of issues within a matrix of competing demands and tasks, together with individual and more complex system dynamics, with intention, knowledge, and awareness. The social work perspective is to treat the individual in the context of, and in dynamic exchange with, his or her environment. In complex healthcare situations, this is a very useful framework to utilize on behalf of families. The social worker thus becomes the ally of the family in negotiating the complexities of the unfolding care situation of their child.

Another important task is the discussion with the parents—and the patient, as appropriate—about their goals. Decisions can then be made in light of the overriding goals of the family. Sometimes there is a need to help the family negotiate the goals within the family before they can effectively deal with the medical system.

One example is a case in which an 18 year old did not want a leg amputation in order to *possibly* prolong her life in light of her terminal diagnosis. Her parents wanted her to have the amputation in order to *potentially* gain more time with her regardless of loss of function and body image.



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Meanwhile there were differing opinions among the doctors (from two different healthcare systems) about a possible amputation and whether or not it should even be offered. Some believed that it was the best way to get good pain control, while others thought it could create new pain issues for her.

In this case the social worker met with the patient, the parents, and then the family. The social worker also asked a health system ethicist to meet with the patient to help her review her options and make a decision. The social worker also met with the patient's oncologist to review the conflicting recommendations around the possible amputation. In this case there were issues of physical, emotional, and spiritual pain. Ultimately the social worker asked for support from the primary doctor, ethicist, and chaplain, as well as meeting directly with the patient and family to help them with the decision.

In the meeting with the patient, the social worker supported the patient in talking about why she did not want the amputation and her awareness of what her parents wanted her to do. She needed to weigh her wishes against the wishes of her parents as well as the recommendation of her primary physician. She said yes to meeting with the ethicist in order to meet with someone who did not know the parents or her and would be able to guide her through a decision making process that felt comfortable to her.

The social worker asked the oncologist (chosen by patient as the one she wanted a final recommendation from about possible amputation) to review all the conflicting medical opinions and to talk to the patient to summarize the findings. He agreed to do this and was comfortable making a recommendation to her. The oncologist made his recommendation to her before the ethicist met with her to make a decision. The social worker coordinated the timing of the ethicist meeting to occur after she received everyone's input (family and doctor).

The social worker provided emotional support to the patient and had sessions with her to encourage her to express her fear and anger around the possible amputation. Self-hypnosis was taught to the patient in response to her anxiety. She ultimately decided to have the amputation procedure and hypnosis was then focused on her gaining control over phantom limb pain/sensations. The diverse skills possessed by the social worker enabled her to respond to this teen's issues as they arose, in a context that benefited from established trust and offered continuity of care.

Because of the strong interdependence and affective bonds between children and their families, it is not uncommon for an "enmeshed" picture of pain to emerge, especially at points of increased emotional distress, like a new diagnosis, or when death is approaching. Parents may perceive their child to be comfortable when outside observers are concerned about signs and symptoms of increased pain. Children may underreport pain when they see that parents cry at the news of their pain being more intense or new in an effort to help their parents feel better. It can be difficult to gauge whose pain we need to treat. The answer of course is both.

These are different kinds of pain and suffering, with understandable roots in emotional, spiritual, and psychological dimensions of personhood. They are not necessarily pathological, but rather typical reactions to overwhelming distress with high stakes involved, and as such need to be addressed in normalizing frames. The goal is to help move the family system in the direction of more effective coping with the wide range of issues facing them. Sometimes this can involve a process of naming all the different issues, and identifying resources for addressing a multiplicity of needs under highly pressured circumstances. Theoretical approaches like single-session or solution-oriented therapies have much to offer social workers practicing in this arena, as we often have little control over how much time we may have to work with a particular child and family.

In the context of a well-integrated team approach to care, strategies for supporting families and children are often divided up among various team roles along lines like expediency, rapport, timely access, and special expertise. The social worker can help the team keep the larger system dynamics in mind and so



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enhance the team's capacity for effective support to the child and family. The social worker may provide direct care to the child and family, or indirect services to the family by assisting the team in more effectively working with the family.

In sum, the social work role on the pediatric palliative care team is a flexible and fluid one, shifting focus from family and patient issues to system barriers and dynamics as needed, but always keeping the goals of the patient and family in focus. The social worker functions as a counselor, but also as a mediator between the family system and the healthcare system, addressing concerns as they arise, supporting the child through empowering, and supporting the family upon which the child depends. As a profession, we seek to empower the children and families that receive our care, and to help all those involved negotiate the stormy waters of a child's experience with life-threatening illness and death.

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SPIRITUAL SUFFERING SCALE: A TEACHING TOOL

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Spiritual pain is defined here as emotional distress due to spiritual and religious issues. Spiritual issues that may result in emotional distress include:

- theological and belief issues, such as:
 - inability to participate in usual religious practices
 - a belief that God is punitive
 - incongruence between experience and beliefs
 - troubling beliefs about dying, death, or afterlife
- existential and meaning issues, such as:
 - loss of a sense of meaning, loss of role which gave meaning
 - loss of a sense of hope; letting go, and grief and anger
 - loss of a sense of dignity, or loneliness
- relationship issues, such as:
 - difficulties in relationship with God, or a sense of God's absence or failure, or a sense of a need for forgiveness
 - difficulties in relationship with loved one, or broken relationships, or a sense of need to forgive or be forgiven, or need to let go of expectations
 - negative sense of self-value, or feelings of guilt or regret in life lived

SPIRITUAL SUFFERING LEVELS

0. No end-of-life issues causing spiritual distress. Patient focused on issues that are bringing a sense of spiritual well-being. This is for patient who has no life regrets and no family issues and is ready for death.
1. Patient puts little focus on life events which are possible sources of spiritual distress during end-of-life, and most focus on issues of well-being.
2. Patient puts some focus on issues which cause spiritual distress, but does not acknowledge distress; puts focus on drawing from sources of spiritual well-being and coping.
3. Patient expresses minimal spiritual distress from life issues, but more focus on issues of well-being.
4. Moderate distress from issues noted. Patient acknowledges the distress, but continues to also focus on sources of well-being.
5. Moderate distress issues noted, with little focus remaining on sources of well-being.
6. Moderate suffering from one or more issues noted, dominating the patient's focus. Patient either unable to draw from sources of spiritual well-being or has not identified sources.
7. Severe suffering from one or more issues noted. Patient still able to draw from sources of well-being.
8. Severe suffering from one or more issues noted. Patient having difficulty drawing from sources of well-being.
9. Severe suffering from one or more issues noted. Patient unable to find relief through humor or distraction, with little or no ability to draw from sources of well-being.
10. Severe, unbearable suffering from one or more issues noted. Loss of hope; utter despair.



THE INTERNATIONAL CHILDREN'S PALLIATIVE CARE NETWORK

What is the ICPCN?

The International Children's Palliative Care Network (ICPN) aims to be a "one-stop" international resource providing information about pediatric palliative care services for funders, professionals, caregivers, and families through a Web site and e-newsletters. Its vision is to raise the profile of children's palliative care while fostering an awareness of the worldwide need for children's palliative care services.

Originally conceived in 2005 by a group of dedicated individuals who wished to facilitate the widespread sharing of useful knowledge and experience for the benefit of the thousands of life limited and life threatened children around the globe whose voices often go unheard.

With the significant and ongoing support of The True Colours Trust, the organization launched its Web site in 2007 and began an online register for all children's hospices and children's palliative care programs. The Web site www.icpcn.org is also updated on a weekly basis with relevant news and event information from around the world.

At present the ICPCN is managed by a steering group made up of pediatricians, professionals, and recognized leaders who work in the field of palliative care for children in eight separate regions of the world. This steering group is currently chaired by Joan Marston, Pediatric Palliative Care Manager for the Hospice Palliative Care Association of South Africa (HPCA). The position of its International Information Officer, who co-ordinates the network from within South Africa, is also hosted by the HPCA.

The ICPCN represents the voice of children on the Worldwide Palliative Care Alliance (WPCA).

Why was the ICPCN formed?

Fewer than 25 countries around the world have dedicated children's hospice and palliative care services and in many instances people are unconnected and there is a lack of access to good information. As a network of individuals and organizations all working towards the same goal, whatever experiences, expertise, and available information there is in one organization, can be accessed and shared by all.

What has the ICPCN achieved to date?

- Membership of the ICPCN has shown rapid growth and at present stands at over 120 organizations and more than 200 individuals, representing 31 countries worldwide.
- The Web site is kept up to date with relevant news and events from around the world and members are encouraged to upload information and research pertaining to their own hospices and organizations.
- Four quarterly e-newsletters have been published dealing with issues relevant to the field and articles which highlight advances and challenges experienced in both developed and developing countries around the world.
- Members are sent reminders of upcoming events and abstract submission dates.
- Funding has been secured for the initiation of a program in early 2009 of expertise-sharing through the awarding of scholarships and bursaries, focusing initially on pediatric palliative care leaders in resource poor countries.



The ICPCN Charter

To coincide with World Hospice and Palliative Care Day on 11 October 2008, the ICPCN launched its International Charter for the Rights of Life Limited and Life Threatened Children. With grateful acknowledgement to the ACT Charter, the ICPCN Charter sets out the *international* standard of support that is the right of all children living with life limiting and life threatening illnesses, and their families.

The Charter calls for all children who need it to receive appropriate palliative care – care whose main purpose is to relieve suffering, whether physical, spiritual, or emotional, and to promote quality of life and dignity in death.

It also focuses on the rights of the parents or primary care givers and other family members of the affected child and calls for an undertaking that the child and the child's family be respected as equal partners in decision making related to care, treatment, and symptom control.

The ICPCN wishes to see the Charter ratified and endorsed by governments and health departments in every country and encourages anyone who so desires to use it as an advocacy tool.

This Charter is available in 20 languages and can be downloaded directly from the Web site.

What does the future hold?

Future plans for the ICPCN include the drawing up of an inventory of available education and training in Pediatric Palliative Care worldwide, an international mapping of hospice and palliative care programs, and research into the unmet needs of people working in the field, leading to a global plan of development and the capacity to show gaps to interested funders.

The ICPCN is partnering with Children's Hospice International to present the 20th CHI World Congress to take place in Cape Town, South Africa, from 14 – 16 September 2009. For more information on this congress and abstract submissions, please visit the ICPCN Web site or go to www.chionline.org

Who can join the ICPCN?

The ICPCN is open to both organizations and individuals who either work in the field of pediatric palliative care or in a related field. Membership is completely free and carries no obligations. You can join via the Web site at www.icpcn.org.uk

For any queries or for more information, please feel free to contact Sue Boucher, ICPCN International Information Officer, at info@icpcn.co.za.

Readers will find the ICPCN Charter of Rights for Life Limited and Life Threatened Children on the following page. This document and additional information can be found on the ICPCN Web site at: <http://www.icpcn.org.uk/page.asp?section=000100010014§ionTitle=Charter>



The ICPCN Charter sets out the International standard of support that is the right of all children living with life limiting or life threatening conditions and their families.

**THE ICPCN CHARTER OF RIGHTS FOR LIFE LIMITED
AND LIFE THREATENED CHILDREN**

1. Every child should expect individualised, culturally and age appropriate palliative care as defined by the World Health Organization (WHO). The specific needs of adolescents and young people shall be addressed and planned for.
2. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.
3. The child's parents or legal guardians shall be acknowledged as the primary care givers and recognized as full partners in all care and decisions involving their child.
4. Every child shall be encouraged to participate in decisions affecting his or her care, according to age and understanding.
5. A sensitive but honest approach will be the basis of all communication with the child and the child's family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.
6. Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.
7. Wherever possible, the child and the family should be given the opportunity to consult with a paediatric specialist with particular knowledge of the child's condition and should remain under the care of a paediatrician or a doctor with paediatric knowledge and experience.
8. The child and the family shall be entitled to a named and accessible key-worker whose task it is to build, co-ordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources.
9. The child's home shall remain the centre of care whenever possible. Treatment outside of this home shall be in a child-centred environment by staff and volunteers, trained in palliative care of children.
10. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required.

With acknowledgement to the ACT Charter

"Palliative care for children is the active, total care of the child's body, mind and spirit, and also involves giving care to the family. It begins when the illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres, and in children's homes." - World Health Organization, 2002.

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Readers' Corner

Article: C. A. Knapp, L. A. Thompson, W. B. Vogel, V. L., Madden, & E. A. Shenkman. Developing a pediatric palliative care program: Addressing the lack of baseline expenditure information. *American Journal of Hospice and Palliative Care* OnlineFirst, published on December 1, 2008, as doi:10.1177/1049909108327025.

Abstract: An estimated 500,000 children annually cope with life-limiting conditions expected to lead to premature death, but little is known about their healthcare expenditures at the end of life. This information is crucial for health planners to propose pediatric palliative care programs. This study aims to estimate predicted healthcare expenditures for Medicaid-eligible infants and children across several health service categories. Across these categories, infants and children were predicted to spend about US\$110,000 and US\$62,000 at the end of life, respectively. About 5% of infants and 8% of children incurred hospice expenditures. Results from the multivariate models suggest that black, non-Hispanic children are less likely than white, non-Hispanic children to use hospice care. Baseline expenditure information from this study can be used to develop integrated pediatric palliative care models. Our findings also suggest that many more children could potentially benefit by using hospice care at the end of life.

Who is the audience for this information? This article has a very focused audience: Those people who need additional data to help justify, develop, or fund a pediatric palliative care program; those who may be involved in advocacy/legislation/policy development, and those who may be fund raising.

What is special about this article? To my knowledge, as inpatient, outpatient, and hospice costs in the last year of life are included, this information is not available elsewhere. This article is not easy to read. Perhaps that is because it is written mostly by statisticians and epidemiologists. But those of use who wish to disseminate the model of pediatric palliative care will benefit from this baseline information. To my knowledge, as inpatient, outpatient, and hospice costs in the last year of life are included, this information is not available elsewhere. Also this information supports what many of us have experienced. Racial disparity in access to and utilization of hospice services exists.

Where and how can I apply this information? This information is not applicable to most of us clinicians who care for children. It is pertinent to planners, administrators, advocates, and dreamers who wish to make pediatric palliative care a reality for more of our children with life-limiting conditions.

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Items of Interest:

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

- 1. Subjects and Contributors for Future Issues of This Newsletter.** In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, and unsung heroes in the circle of care. In some of our early issues, we also included four articles by Dr. John Saroyan (sometimes writing with colleagues) on assessment and pharmacologic management of pediatric pain, touching on such topics as neuropathic pain and usage of methadone. In this issue and in the one that preceded it, we are examining issues related to **pain and symptom management for children with life-threatening illnesses and their families.**

For future issues, we are considering subjects that focus on preparing families for transitions (e.g., moving a child from one program/system to another, taking a child home, coping with a child who dies at home), overcoming barriers to 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; Mary Kay Tyler at mktyler@hospicewr.org; or Chuck Corr at charlescorr@mindspring.com. We will work with you!

- 2. NBCHPN Pediatric Certification Exam Survey.** The National Board for Certification of Hospice and Palliative Nurses (NBCHPN) is assessing the need for a pediatric hospice/palliative certification program. We ask that you consider completing the survey related to this opportunity through the link below. The survey will take about 15 minutes to complete and will be open through February 28, 2009. This invitation may be forwarded to other registered nurse colleagues who may be interested in this topic.

<http://www.zoomerang.com/Survey/?p=U2BGZDUDDTR7>

Thank you in advance for your attention,
Kerstin Mc Steen, MS, APRN, ACHPN
President, NBCHPN

- 3. Upcoming Meeting.** The American Academy of Hospice and Palliative Medicine (AAHPM), in collaboration with the Hospice and Palliative Nurses Association (HPNA), will host its Annual Assembly on March 25-28, 2009, at the Austin Convention Center in Austin, Texas. For further information, visit the Academy's web site at www.aahpm.org or call 847-375-4712.
- 4. Pediatric Palliative Care at Clinical Team Conference.** ChiPPS is proud to have created the first Pediatric Intensive that was part of NHPCO's 9th Clinical Team Conference held in Dallas, October 2008. A Pediatric Intensive will be offered at the 10th Clinical Team Conference to be held in Denver on September 24-26, 2009; look for news from NHPCO later in the year.

ChiPPS encourages you to watch the NHPCO Web site for opportunities to submit an abstract/proposal to future conferences!

- 5. Online Pediatric Listserv.** NHPCO and ChiPPS remind readers of the special pediatric listserv for NCHPP or eNCHPP members who provide services for children with life-threatening conditions and their families. [Read more](#) about the listserv and eligibility requirements to participate. [Join the pediatric listserv.](#)



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



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6. **Calendar of Events.** As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpc.org/pediatrics. *ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpc.org/pediatrics.* Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the **Communications Preferences** tab in your individual member record online and "opt-in" for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800/646-6460.

Visit the ChiPPS Web page at www.nhpc.org/pediatrics for further materials and resources of interest.

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