Symptom Management with Children
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Issue Topic: Symptom Management with Children

Welcome to the 46th issue of the ChiPPS E-Journal. This issue of our E-Journal offers a collection of articles that explore selected issues in managing various symptoms with children. These articles complement those in Issue #45 that focused on pain management in children. The present issue offers suggestions for and examples of engaging in this important aspect of providing pediatric palliative/hospice care. We appreciate that a single issue on this subject will not do complete justice to this very broad subject area, but we hope that the articles in this issue will spur increased awareness and discussion of this subject. We welcome communications from anyone who has more to offer on these subjects.

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

Comments about the activities of ChiPPS, its E-Journal Work Group, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at christytork@gmail.com.

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“Moments of Grace” in Dying, Death, & Bereavement  
Ann Fitzsimons, BS, MBA  
In this reflective piece, Ann offers three “examples from my own life that might provide some inspiration as to what and how ‘Moments of Grace’ can happen when someone is open to what’s possible during someone’s dying and after someone’s death.” Her hope is “that more healthcare professionals, including physicians, realize how small acts of kindness can reap huge, beneficial rewards for patients and their families when the child is going to die, is actively dying, or has just passed away.”

It’s Never a Bad Idea to Make the Referral  
Genny Jessee, June’s mother  
The mother of a child born with an undiagnosed neurological disorder who developed multiple complications relates that June saw a total of “20 specialists across four different hospitals in three different states” before dying shortly before her fourth birthday. Ms. Jessee writes that, “Despite all of these doctors [whom she praises as individuals], we didn’t learn about palliative care until a year before her death, and by pure luck.” She then explains how palliative care helped her daughter and June’s parents and shows how it could have helped sooner.

Managing Nausea and Vomiting in Children  
Alternative Routes of Medication Administration in Children  
Melissa Hunt, PharmD  
These two articles by our resident pediatric clinical pharmacist offer clear, thorough, and useful guidance in the subjects they address that will be of importance to many professionals who provide pediatric palliative/hospice care.

Fatigue in Children with Serious Illness  
Jori F. Bogetz, MD, and Margaret Root, MSN, RN, CPNP-AC, CHPPN  
“Through case vignettes, this article explores the multifactorial nature of fatigue in seriously-ill children, assessment strategies, and effective treatment options.”

Understanding Silence: Symptom Management in Children Who are Severely Delayed and/or Diagnosed with Disorders of Consciousness  
Vanessa Andrews, MA, CCLS, ATR-BC, LCAT, CEIM, RPT  
How does a professional care provider cope “with the challenge of managing symptoms in a population that cannot communicate with words, advocate for their needs, or even play like a typical child can and does?” This article argues that “each of these spectacular kiddos have something to say after all, as long as there is someone there to listen, ever so carefully.” The article suggests ways that professionals and family members can help such children.

Existential Pain in Children and Teens  
Rabbi Naomi Kalish, MA, ACPE, BCC  
It is challenging to know and understand what a child or teen with existential pain is thinking and experiencing. In this article, Rabbi Kalish argues that care providers must approach such youngsters and their pain within the context of relationship, beginning within the family system, acting as a midwife to self knowledge, and helping to achieve existential meaning through rewriting a sense of purpose.
Using Reiki Therapy for Symptom Management in Children Receiving Palliative or Hospice Care  

Susan Thrane, PhD, MSN, RN  
Dr. Thrane advocates in this article for the value of Reiki Therapy, defined “as a complementary practice wherein practitioners place their hands lightly on or just above a person, in discrete positions, with the goal of facilitating the person’s own healing response.” Although conceding that further research is needed, she states that, “There is a slowly growing body of evidence showing mostly positive results for the use of Reiki therapy for symptom management in both adults and children … Children and adolescents are accepting of Reiki and most complementary therapies … [and that] Reiki, because it is a gentle, relaxing, non-invasive touch therapy, can provide comfort during palliative and hospice care.”

Palliative Sedation for Intractable Suffering at End of Life in Children  

Suzanne S. Toce, MD  
In this article, Dr. Toce describes palliative sedation as “management that limits the child’s awareness of suffering that is intolerable and intractable with the goal of relieving symptoms and suffering to a level acceptable to the child/adolescent.” The article describes assessments and criteria involved in palliative sedation, barriers to optimal pain and symptom management, appropriate setting and timing, other life-prolonging treatments, contrasts with physician-assisted suicide or euthanasia, pitfalls in palliative sedation decisions and who should be involved, the medications used, and what should occur after death. Finally, Dr. Toce notes that “Aggressive symptom management by trained providers, along with advance care planning, will in many cases obviate the need for pediatric palliative sedation.”

Handbooks for Pediatric Pain and Symptom Management  

Suzanne S. Toce, MD  
Dr. Toce presents several tools that can be used by those with little training or infrequent exposure to pediatric palliative care patients managing basic symptoms as well as adult providers caring for a child. As with all resources, we recommend consulting a pediatric care provider at your regional medical center if pain or symptoms are complicated.

ADDITIONAL NOTES  
ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.  
Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.  
Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to 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 previous issues of this E-Journal, additional materials, and other resources of interest.

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“MOMENTS OF GRACE” IN DYING, DEATH, & BEREAVEMENT

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“At the end of the day people won't remember what you said or did, they will remember how you made them feel.”
-Maya Angelou

Life, in general, is messy—dying, death, grief, and bereavement even more so. And when it's a baby, infant, child, teen, or young adult who is dying, or who has died, it's harder, tougher, and plain out messier. There is plenty of training for the clinical skills of caring for children while they are sick, not as much, yet, for while they are dying, and even less still for what to do after the child has died. Who takes care of the child, the bereft family...and how, in a way that will be meaningful (and hopefully not any more painful) for the family?

Different health systems presumably have their own policies about how pediatric deaths are handled and what kind of follow-up is done with the family to check in on them in their grief/bereavement after the child has died. It's not the purpose of this article to go into all that. Instead, I'd like for this piece to try to create an awareness of finding little things that each member of the healthcare team can do when a child has died. That is, to find words and actions that, while they may seem insignificant to the child's healthcare team, might bring worlds of healing to the family in the days, weeks, and even years following the child's passing. I call these “Moments of Grace.”

For the clinicians reading this, unfortunately there isn't a list to reference as to what these “moments” are; instead, they're organic...they just happen and present themselves. The trick for each member of the healthcare team is to be truly aware and “present in the moment” with the child and his/her family at and after the time of death so that they can see these grace-filled opportunities and try to act on them. These opportunities are not to be written off as the job of just one or two members of the team—say the chaplain or a social worker—no, they are moments for each team member to empower themselves to think and act in a way that will bring peace and healing to the family during and after their child’s death. These moments may start with a spark, an intuitive feeling that just moves an individual to do or say something that may just feel like a passing thought, but it could just be the/a lifeline that will pull the family through their experience so that they can hopefully remain “whole” on the other side of this pediatric death.

What follows are a few examples from my own life that might provide some inspiration as to what and how “Moments of Grace” can happen when someone is open to what's possible during someone’s dying and after someone’s death.

At the time of my Mom’s passing at 68 from early onset Alzheimer’s, she was being cared for in a nursing home in a room she shared with an elderly woman, Gladys, who was also suffering from dementia. When my Mom died, they took Gladys out of the room to allow us time with my Mom in private. However, as the hours passed before the funeral home could come and pick her body up, one of the nurses realized that Gladys was really upset and was asking to see my mom, so the nurse asked me if it was OK if Gladys could pay her respects. I thought it an odd request, but of course said yes, not really thinking it would matter much to Gladys given her cognitive state, but it did. In that “Moment of Grace,” Gladys sat by my Mom’s bed, said good-bye, and wept. For those few minutes, Gladys was lucid and fully present, realizing what had happened. Gladys then turned to get up, found me standing at the door, and gave me a big hug through tears and said, “I’m so sorry. I lost mine too.” Her hug, her words, her ability to connect with me on a human level were so powerful and so filled with grace that I could immediately feel the healing that was occurring for both Gladys and me. I was thankful for the perceptive nurse who realized what Gladys needed in that moment—to see my Mom and say good-bye—and because out of that, we both received gifts beyond measure.

On another occasion, when my infant niece, just a week old, was being tested to determine her prognosis as she was born with a malignant brain tumor that was undiagnosed in utero, I paced the halls waiting for scan results to see what, if anything, could be done to help save her life. My sister was still in the suburban hospital where my niece was born, but my niece and I were at a children’s hospital where she had been transferred to get access to...
the specialized care she would need. We were waiting for a consult with the pediatric neurosurgeon as to her prognosis and when it finally happened, it felt staged, rehearsed, uncomfortable. The news was not good and the healthcare team was not comfortable at delivering it to us—and it showed. Afterwards, all I wanted to do was to sit by my niece’s isolette in the NICU and somehow let her know how much we loved her, no matter how little or much time she had left. One of her NICU nurses, who had been in the consult with me, came up to me and, as I shared this hope with her through many tears, turned to me and said, “She knows you love her.” Now in reality, there is no way this one-week-old infant with this massive brain tumor could “know” that, but I’ll never forget the nurse’s kindness in acknowledging that my niece did (even if it wasn’t rational) because it’s what I needed to hear in that moment. My niece did die a week after all this and even this many years later, I’ve not forgotten the support and kindness of that intuitive nurse.

And lastly, when my sister was dying and we had decided to transition to hospice care and have her come home to die in my house, her oncologist came and visited with us before she left the hospital. It was a long visit (over an hour), which surprised me given we both knew how busy he was with his practice and teaching in the Med School. But in that visit, it allowed my sister the opportunity to say what she needed to say to him, which was to thank him for getting her through her cancer journey at parts when she didn’t think she could. It also allowed him the chance to say good-bye and to tell her how much he’d hoped she’d get more time and that he was sorry. As he did so, he wept at her bedside, as did she and I, and in that “Moment of Grace” of shared tears, healing began for all of us. Of course her oncologist had other things to do, but he knew this was important to my sister (and maybe somewhere inside, to his own processing of her impending death), and so he seized the moment. Ten years later, it’s one I still treasure for me and because I know it brought my sister peace.

So while there is no “evidenced-based” practice to say how important finding and capitalizing on these “Moments of Grace” are, there are a lot of anecdotal stories that certainly support why it’s important. It’s my hope in bringing this notion to light, that more healthcare professionals, including physicians, realize how small acts of kindness can reap huge, beneficial rewards for patients and their families when the child is going to die, is actively dying, or has just passed away. No member of the team should ever overlook what impact a kind word, a touch, a smile, a tear, a reassurance, or a hug can have. It may be just what that child or family needs to have happen at the moment to get them through to whatever is next. Healthcare professionals should also not be shy to share a favorite remembrance of the child that they have with the family. Let them know and see that their child means/has meant something to you and to your team, and that he or she was more than just a patient, but another fellow human being who had value and who mattered.

As I reflect back on the examples presented here, I remember the kindness of strangers—a nurse who facilitated a Good-bye for a roommate who needed it, and who in turn, gave me the validation and support I needed at the time of my mom’s death; a NICU nurse who knew what I needed to hear to make me feel better about getting a life-ending diagnosis for my infant niece; and a physician who took the time out of his busy day to really listen to a patient and grant her one of her last wishes—an opportunity to say good bye and to thank him. And while none of this may not be rocket science, this “seeing” with humanistic eyes chances to make a difference, to bring or create grace, or to bring healing to the family at the time of or after a child’s death, is part of patient and family-centered best practices, and may be the very best part. It’s the human-to-human part that can’t really be taught in a classroom or a textbook, but instead, observed and learned from trial-and-error experiences when seeing a chance to do something small with compassion during or after a child has died to allow for grace to enter that space and situation.

There is a saying that “God is in the details” and I think that whomever or whatever higher power is acknowledged, there is great wisdom in this saying, especially when it comes to the little things that members of the healthcare team can do near the time when or after a child has died. In the end, the family will remember how members of the team made them feel. So with each pediatric death the team is involved in, they may want to think about asking themselves these questions.

- How is the family feeling as they leave their deceased child behind at our healthcare institution?
- How did my/our actions make the situation better? Worse?
- Did I/we find and capitalize on any “Moments of Grace” that they are taking with them that they can hold onto and carry with them through their grief and bereavement?
- If not, did I/we miss any grace-filled opportunities and how might I/we do it different the next time?
In closing, I share some reflections taken from The Art of Grace website about approaching these experiences with dying and deceased children, and their families, with an innate awareness and intention that each member of the team can make it better by bringing light and grace to what can be a dark place for some. Seize the "Moments of Grace" when they are presented and healing will begin for all who are touched in that space.

I am a sage in training.
I am aware of the precious present.
If I know better, I do better.
Now is where attention and intention intersect.
Insight from the past guides me in the future.

My worth is not determined by my mood or my thoughts.
I embrace the awareness that pain gives me.
I celebrate the wisdom gained from making mistakes.
When I go into darkness, I bring a light.

I am enriching the Universe.
Creativity is a gift to us. Using our creativity is our gift back to All.
I am the abundance of Life bursting forth unreservedly in my life and in all those with whom I have any contact.
As we move toward our dreams, we move toward our joy.
Creativity is the natural order of life. Life is energy: pure, creative energy.
Energy is connection between past and future, between point A and point B, between you and me.
In solitude, I remember my connection to others.
I don’t expect to find the light in all situations, but rather to radiate the light.

Affirmations sourced from The Art of Grace website: http://www.artofgrace.org/affirmations.html
It is never a bad idea to make the referral

Genny Jessee
June’s mother – St. Louis, MO
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June had an undiagnosed neurologic disorder that began, for us, the morning after her birth when she failed the newborn hearing screening at the hospital. Infantile spasms started not long after, eventually numbering in the hundreds to thousands each day. As her issues compounded—cortical visual impairment, developmental delays, nephrotic syndrome, bowels that simply stopped working—we took June to one specialist after another, leaving with more questions than answers as to the underlying cause of her symptoms and with mere temporary solutions. As parents, we lived in a constant state of worry and unknowns about her health and future. Desperate to find a cure, we turned to experimental therapies, and even moved our family hundreds of miles from home...without success. June’s kidneys failed two months’ shy of her 4th birthday. She could no longer take in fluids without liquid pooling in her lungs. That’s when my husband and I decided to listen to June and what her body was telling us. She was ready to die.

The thought that June wouldn’t live past childhood came to us late in her life. In hindsight, I think we would have benefited from clear, honest, and direct conversations from June’s physicians earlier on.

In total, June saw 20 specialists across four different hospitals in three different states. Despite all of these doctors, we didn’t learn about palliative care until a year before her death, and by pure luck—the hospital where June’s feeding tube surgery was performed has a policy that the palliative care team follows all complex children that are admitted. I am so thankful for this policy. Individually, we had a fantastic relationship with nearly every one of June’s doctors. We trusted each of them, and I know they care deeply for their patients and their families. As a whole, however, I believe the system let us down by not introducing palliative care at the moment we were unable to control her infantile spasms. I believe it would have ushered us into the next stage of her condition in a better way.

The palliative care team helps parents coordinate their child’s care when the growing number of specialists can quickly become overwhelming. I know June’s doctors communicated with one another in their notes, but to us each specialty felt separate from the other, and it seemed that the care of June as a whole person was lacking. I felt tossed around to each specialist like a hot potato. I questioned if anyone was putting the pieces together. I understand that coordination of care is an enormous problem in all areas of healthcare, and I don’t have a solution to propose. However I think palliative care can aid families in this dilemma until we figure out how to resolve it. At the very least, palliative care providers can be the point person for parents desperate to make sense of all the different ailments and how they relate to their child.

Another vital role of palliative care for a family like ours is to educate parents on what they can expect in their child’s life and likely death. My husband and I hadn’t experienced chronic illness or death until it was happening to our first baby. While you pediatric doctors, nurses, and healthcare professionals see sickness and death more often than you’d like to talk about, most of your patients’ parents are facing it for the first time. June’s was a unique scenario and I appreciate that without a diagnosis, there was no way to tell how her condition would unfold. We asked questions about what to expect for June’s life and most of what we heard was, “it’s unlikely,” “we don’t know,” and “it’s hard to tell.” I would leave the conversations feeling defeated, but I still maintained a glimmer of hope from the doctors’ uncertainty. And hope is so important. I know that. But so too is acknowledging what might also happen. After June’s death, I thought about a few of the conversations, and it is now obvious to me that her doctors did not believe she would live a long, fulfilling life. They saw the imminent danger, and while no one ever misled us, I saw a crack of hope in their seeming uncertainty and took it as a large window.
In hindsight, I wish someone had been clear and upfront with us when we were unable to control her infantile spasms. This wouldn’t have been easy, I know. I would have been angry with you. I would have cried, maybe yelled, and probably stormed out. But as a mother on the other side of it now, I would much rather have known our likely fate and spent my energy proving you wrong. Even if I didn’t see it at the time, my anger would have been with the situation and not with you. I would have looked back on the conversation now and been grateful for it.

Lastly, palliative care would have helped us manage June’s pain so much sooner. June suffered from the day she was born. In the first few weeks, she cried all the time. I remember telling the pediatrician at her one month checkup that it seemed like something was hurting her because she screamed so much. He brushed it off as colic, but when the spasms became obvious her crying episodes made much more sense. During our first encounter with the palliative care doctor, on the other hand, she noticed June would cry out in pain for no reason at all. I wanted to hug her as soon as she mentioned it because that is what I had been saying for so long! And, guess what?! She had a medicine to help with that.

June’s palliative care doctor was a great support to us, and once we were set up with her, the last year of June’s life was mostly peaceful. Our appointments focused on June’s comfort and everyone’s quality of life. I used to be afraid to ask about June dying to other doctors because I thought they would think I wanted her to die. With our palliative care doctor, we could ask questions freely and openly. She was our lifeline, and I am so grateful to her. Being June’s mom is both incredibly rewarding and exhausting a physically and emotionally draining process. For parents like me, some of these hardships are out of our control and some are in our control. Making life easier for families like ours through palliative care is within your control. When you see the writing on the wall, don’t be afraid to recommend palliative care. It could be just the thing the family needs.

This article first appeared on pp. 5-6 in the December newsletter of the American Academy of Pediatrics’ Section on Hospice Palliative Medicine. It is reprinted by permission of both the AAP SOHPM and the author.
MANAGING NAUSEA AND VOMITING IN CHILDREN

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Nausea and vomiting are common symptoms seen in children at end of life. Children are at a higher risk of developing consequences of prolonged nausea and vomiting (e.g., dehydration, electrolyte disturbances, etc.) and these symptoms can be distressing to the patient and family. Therefore, prompt recognition of the potential cause and appropriate treatment is necessary.

Pathophysiology of Nausea and Vomiting

The pathophysiology of nausea and vomiting is complex. The vomiting center located in the brain receives input from various areas within the brain as well as from the gastrointestinal tract. The cause of nausea and vomiting might be multifactorial. The primary neurotransmitters that mediate these systems include dopamine, histamine, acetylcholine, and serotonin. The figure below indicates the four major mechanisms for stimulation of the vomiting center (Figure 1).

Figure 1. Mechanisms Involved in Nausea and Vomiting

The Chemoreceptor trigger zone (CTZ) is located in the area postrema of the medulla. Nausea and vomiting are stimulated here by chemotherapeutic agents, bacterial toxins, metabolic products (e.g., uremia), and opioids. Dopamine (D2), serotonin (5-HT), and neurokinin-1 are the primary neurotransmitters involved in this process. Therapy is based on blocking D2 with dopamine antagonists including butyrophenones (haloperidol), phenothiazines (chlorproMAZINE, prochlorperazine, promethazine), and metoclopramide. 5-HT3 antagonists (ondansetron), also active here, are mainly used for chemotherapy and radiotherapy-induced nausea. 5-HT3 antagonists also have a multitude of safety and efficacy data in pediatric patients of all ages, with lower risk of side effects than other classes.

Cerebral Cortex induced nausea and vomiting can be caused by anxiety, taste, and smell, as well as increased intracranial pressure (ICP). Corticosteroids are useful to decrease ICP. Anxiolytics, such as benzodiazepines, are used to treat “anticipatory” nausea and gustatory and olfactory over-stimulation.
Vestibular nausea and vomiting is triggered by motion. Opioids can sensitize the vestibular center, resulting in movement-induced nausea. Ambulatory patients are more susceptible to vestibular nausea and vomiting than bedbound patients. Since histamine (H₁) and acetylcholine (ACh) are the predominate neurotransmitters, antihistamines (diphenhydrAMINE) and anticholinergics (glycopyrrolate, hyoscyamine) are the drugs of choice in movement-induced nausea and vomiting.

Gastrointestinal (GI) tract stimulation occurs through vagal and sympathetic pathways. These pathways can be triggered by stimulation of either mechanoreceptors or chemoreceptors located in the gut. Gastric stasis, gastrointestinal obstruction, medications, metastatic disease, bacterial toxins, chemotherapeutic agents, and irradiation, can lead to nausea and vomiting. Glossopharyngeal or vagus nerve stimulation in the pharynx by sputum, mucosal lesions, or infection can also evoke nausea. The major neurotransmitters in the upper GI tract are D₂, acetylcholine, and 5-HT. Metoclopramide blocks 5-HT₄ (at high doses) and increases gastric motility above the jejunum. Anticholinergics decrease both GI spasticity and motility in nausea induced by gut hyperactivity.

Autonomic failure causes gastroparesis resulting in anorexia, nausea, early satiety, and constipation. Delayed gastric emptying is frequently observed in patients with diabetes mellitus, chronic renal failure, and neurological disorders. Malnutrition, cachexia, lung and pancreatic cancers, human immunodeficiency virus, radiotherapy, and drugs such as opioids, anticholinergics, antidepressants, and vasodilators have been associated with autonomic failure and resulting chronic nausea, poor performance, tachycardia, and malnutrition.

<table>
<thead>
<tr>
<th>CTZ</th>
<th>Cerebral Cortex</th>
<th>GI Tract</th>
<th>Vestibular</th>
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<tbody>
<tr>
<td>Autonomic dysfunction</td>
<td>Anxiety</td>
<td>Constipation</td>
<td>Motion</td>
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<td>Infection</td>
<td>Cyclic vomiting</td>
<td>Gastropareisis</td>
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<td>Medications</td>
<td>Fear</td>
<td>Obstruction</td>
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<tr>
<td>Metabolic disorders</td>
<td>Increased ICP</td>
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<td>Radiation</td>
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<td>Ulcers</td>
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Managing Nausea and Vomiting

As with any symptom, management of nausea and vomiting in children starts with non-pharmacological therapies including: acupressure or acupuncture, oral care, avoidance of strong odors or triggers, clear liquids (sipping slowly, possibly off a spoon), small and frequent meals chosen by the child, bland foods (e.g., mash potatoes, apple sauce, sherbet, crackers, toast), relaxation techniques, play, and distraction. If vomiting is prolonged, oral rehydration therapy may be necessary to prevent dehydration.1-3,6-7,11

Numerous factors should be considered when choosing an antiemetic, such as age of the patient and most likely cause. Initial approach to therapy should be based on pathophysiology of the nausea and vomiting and mechanism of action of the agent (Table 2). Potentially reversible causes of nausea and vomiting should not be overlooked (e.g., anxiety, constipation, gastroesophageal reflux (GER), medications, pain, peptic ulcer disease, bowel obstruction).

Table 2. Pathophysiology Based Approach to Management of Nausea and Vomiting

<table>
<thead>
<tr>
<th>Mechanism</th>
<th>Class</th>
<th>Receptor</th>
<th>Medication Options</th>
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<tbody>
<tr>
<td>CTZ</td>
<td>5-HT3 antagonist</td>
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<td>ondansetron (Zofran&lt;sup&gt;®&lt;/sup&gt;)</td>
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<td>Butyrophenones</td>
<td>D2</td>
<td>haloperidol (Haldol&lt;sup&gt;®&lt;/sup&gt;)</td>
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<td>Prokinetic</td>
<td>5-HT4</td>
<td>metoclopramide (Reglan&lt;sup&gt;®&lt;/sup&gt;)</td>
</tr>
<tr>
<td>Macrolide</td>
<td></td>
<td>erythromycin (E-Mycin&lt;sup&gt;®&lt;/sup&gt;)</td>
<td></td>
</tr>
<tr>
<td>Cerebral Cortex: ↑ ICP</td>
<td>Corticosteroid</td>
<td>-</td>
<td>dexamethasone (Decadron&lt;sup&gt;®&lt;/sup&gt;)</td>
</tr>
<tr>
<td>Cerebral Cortex: Anxiety</td>
<td>Benzodiazepine</td>
<td>GABA</td>
<td>LORazepam (Ativan&lt;sup&gt;®&lt;/sup&gt;)</td>
</tr>
<tr>
<td>Antihistamine</td>
<td></td>
<td>H&lt;sub&gt;1&lt;/sub&gt;</td>
<td>hydrOXYzine (Vistaril&lt;sup&gt;®&lt;/sup&gt;)</td>
</tr>
<tr>
<td>Vestibular</td>
<td>Antihistamine</td>
<td></td>
<td>promethazine (Phenergan&lt;sup&gt;®&lt;/sup&gt;) or diphenhydRAMINE (Benadryl&lt;sup&gt;®&lt;/sup&gt;)</td>
</tr>
<tr>
<td>Anticholinergic</td>
<td></td>
<td>ACh</td>
<td>glycopyrrolate (Robinul&lt;sup&gt;®&lt;/sup&gt;) or hyoscamine (Levsin&lt;sup&gt;®&lt;/sup&gt;)</td>
</tr>
</tbody>
</table>

If initial approach is unsuccessful:
- Ensure first line agent dose is optimized.
- Rotate to a different agent based on mechanism.
- Substitute a phenothiazine, such as promethazine (Phenergan<sup>®</sup>), for both H<sub>1</sub> and D<sub>2</sub> receptor antagonism.
  - Promethazine has a US Boxed Warning for risk of respiratory depression in children less than two years of age.
- Consider adding a corticosteroid burst, such as dexamethasone (Decadron<sup>®</sup>). Short courses of corticosteroids may have a role in non-specific nausea and vomiting in addition to their usefulness in reducing intracranial pressure. The mechanism of this action is unknown.18 Risks and benefits should be weighed for long-term use in pediatric palliative medicine.
- Consider adding a low dose benzodiazepine, such as LORazepam (Ativan<sup>®</sup>).

Refractory cases of nausea and vomiting often require judiciously selected combinations of medications from different classes. Even with ideal pharmacological and psychological support, complete resolution of nausea and vomiting may not be possible.

Children tend to exhibit more extrapyramidal side effects from phenothiazines (chlorproMAZINE, prochlorperazine, promethazine), especially when given during acute viral illnesses.19 DiphenhydRAMINE (Benadryl<sup>®</sup>) can be used to treat EPS from phenothiazines. Antihistamines are not approved for use in less than two years of age and should be used cautiously in children less than six years of age.21

Conclusion

Nausea and vomiting are common distressing symptoms seen in children. Drug selection focuses on the probable cause of the symptom and mechanism involved, as well as patient-specific factors (e.g., age).
Key References:


4. Di Lorenzo C. Approach to the infant or child with nausea and vomiting. In: UpToDate, Basow, DS (Ed), UpToDate, Waltham, MA 2012.


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*Children's Project on Palliative/Hospice Services*

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ALTERNATIVE ROUTES OF MEDICATION ADMINISTRATION IN CHILDREN

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Medication administration is a challenge in the pediatric setting for many reasons. These issues are further complicated in the palliative and hospice care setting. As a child approaches end of life it is important to proactively prepare for potential symptoms to ensure effective patient-specific symptom management. This includes evaluating available medication routes to ensure administration will be possible if swallowing becomes difficult.

**Medication Administration**

As patients decline, swallowing typically becomes more difficult. When oral medication administration is not possible, sublingual or rectal routes may be convenient and effective alternatives. Absorption can occur rapidly from these routes with the right drug properties.

**Sublingual (SL) Route of Administration**

Due to the rich vascular supply in the oral mucosa, sublingual medications can be absorbed rapidly; however, prolonged exposure to the oral mucosa is required. This route avoids first pass effects, enterohepatic circulation, and premature degradation by gastrointestinal acidity. SL administration can provide rapid onset, simple administration, and is generally well tolerated. Lipophilic (fat-soluble) and slightly acidic drugs are best suited for sublingual absorption.

<table>
<thead>
<tr>
<th>Table 1. Sublingual Administration of Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tablets can be wetted or crushed and mixed with 1-2 mL of water.</td>
</tr>
<tr>
<td>a. Avoid volumes &gt;2 mL, since liquid will likely leak out of the sublingual cavity.</td>
</tr>
<tr>
<td>2. Allow 5-10 minutes between SL doses or before eating or drinking to prolong drug exposure and promote maximum absorption.</td>
</tr>
<tr>
<td>3. Do not crush enteric-coated or controlled-release tablets for SL administration. Only immediate release preparations should be utilized for SL administration.</td>
</tr>
<tr>
<td>4. Repeated instillations of alcoholic (elixirs) or glycol agents (parenteral drugs) can be irritating to the oral mucosa.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2. Common Hospice Medications that can be given Sublingually</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anticholinergics</strong></td>
</tr>
<tr>
<td>atropine (Isopto Atropine®)</td>
</tr>
<tr>
<td>hyoscyamine (Levsin®)</td>
</tr>
<tr>
<td>diazepam (Valium®)</td>
</tr>
<tr>
<td>LORazepam (Ativan®)</td>
</tr>
<tr>
<td>fentaNYL (Actiq®)</td>
</tr>
</tbody>
</table>

*While morphine (Roxanol®) is commonly administered sublingually in terminal patients, sublingual absorption has been reported as poor with most of the drug in liquid form trickling down the esophagus for oral absorption.
Gastrostomy Tube Administration\textsuperscript{1,4}

Absorption of medications administered through a gastrostomy tube is influenced by the location of the distal end of the tube. Many medications are absorbed in the small intestine; however, some medications are absorbed in the stomach or rely on gastric acid for absorption. Therefore, absorption may be decreased the further down the tip is placed in the GI tract.

Some medication formulations should not be administered through feeding tubes. Enteric-coated or film-coated tablets do not crush well, tend to clump in water, and increase risk of clogging tubes. Crushing extended-release, delayed-release, or sustained-release medications may destroy the delivery mechanism and cause overdose, unless specifically designed to allow opening of capsules and administration of individually coated particles. Buccal or sublingual preparations are not designed for absorption in the GI tract. Carcinogenic, teratogenic, or cytotoxic medications may harm the caregiver if aerosolized particles are inhaled while crushing.

<table>
<thead>
<tr>
<th>Table 3. Gastrostomy Tube Administration of Medications\textsuperscript{1,3}</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Stop continuous tube feedings 15 minutes prior to medication administration and restart feedings 15 minutes after administration.</td>
</tr>
<tr>
<td>a. Hold feedings for more than 30 minutes only if the medication requires longer separation to avoid drug-nutrition interactions (e.g., phenytoin).</td>
</tr>
<tr>
<td>b. If using bolus gastric feedings, then administer medications between feedings.</td>
</tr>
<tr>
<td>c. Medications should not be added directly to enteral nutrition products.</td>
</tr>
<tr>
<td>2. Flush the tube with an appropriate volume of sterile water after feedings are stopped, between each medication, and before feedings are restarted.</td>
</tr>
<tr>
<td>a. Flushing volume (1-15 mL) is dependent on patient’s age, fluid status, and tube size.</td>
</tr>
<tr>
<td>3. Crush solid medications into a fine powder using a mortar and pestle and dilute in 15-30 mL of sterile water before delivery into the tube.</td>
</tr>
<tr>
<td>4. Dilute liquid medications, especially highly concentrated or viscous liquids, with 10-30 mL of sterile water before delivery into the tube.</td>
</tr>
<tr>
<td>a. Dilution volume should be at least a 50:50 dilution.</td>
</tr>
</tbody>
</table>

Rectal (PR) Route of Administration\textsuperscript{1,2}

Rectal administration may be a valuable route when the patient cannot swallow or when nausea or medication volume prevent sublingual administration. Many factors affect rectal absorption including the presence of stool in the rectum, pH of rectal contents, drug formulation, and rectal retention of the drugs administered. The rectum should be clear of feces prior to medication administration if possible. Alkaline medications are usually absorbed more rapidly than suppositories or suspensions. Syrup formulations may need to be diluted prior to administration since their high sorbitol concentration can cause bowel evacuation from osmotic effects.

<table>
<thead>
<tr>
<th>Table 4. Rectal Administration of Medications\textsuperscript{1,6}</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Lubricate rectal dosage forms or devices with water-based lubricant prior to insertion.</td>
</tr>
<tr>
<td>2. Position child on his/her side with knees bent and drawn up toward the abdomen, which is often most comfortable for insertion.</td>
</tr>
<tr>
<td>3. Insert medication as recommended per manufacturer directions or recommendations below</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tablets/Capsules</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Oral dosage forms can be administered rectally as whole tablets or crushed and mixed in water.</td>
</tr>
<tr>
<td>a. Do not crush enteric-coated or controlled-release tablets.</td>
</tr>
<tr>
<td>2. Ensure that the fluid volume is appropriate for the child’s age and size:</td>
</tr>
<tr>
<td>a. Younger children—Instill 1- 5 mL of warm water</td>
</tr>
<tr>
<td>b. Older children/adults—Instill 5 - 10 mL of warm water</td>
</tr>
<tr>
<td>3. Ensure that insertion depth is appropriate for child’s age and size:</td>
</tr>
<tr>
<td>a. Infants—Insert ¼ - 1 inch past the rectal sphincter</td>
</tr>
<tr>
<td>b. Adults—Insert 1 inch past the rectal sphincter</td>
</tr>
</tbody>
</table>
Liquids

1. Oral liquids can be administered rectally if dose can be given in an appropriate volume.
2. Limit liquid drug volumes based on patient size.
   a. Typically 60-80 mL is the maximum volume that does not cause spontaneous expulsion.
   b. Enema volumes for children:
      1. 2 - 6 years: 180 mL (6 oz)
      2. 6 - 12 years: 360 mL (12 oz)
      3. Adolescents/adults: 480 mL (16 oz)

Table 5. Common Hospice Medications that can be given Rectally\(^1,3,7-9\)

<table>
<thead>
<tr>
<th>Analgesics</th>
<th>Anticonvulsants</th>
<th>Antiemetics</th>
<th>Antipsychotics</th>
<th>Benzodiazepines</th>
</tr>
</thead>
<tbody>
<tr>
<td>acetaminophen (Tylenol(^9))</td>
<td>carBAMazepine (Tegretol(^9))</td>
<td>metoclopramide (Reglan(^9))</td>
<td>chlorproMAZINE (Thorazine(^9))</td>
<td>ALPRAZolam (Xanax(^9))</td>
</tr>
<tr>
<td>HYDROmorpheone (Dilaudid(^9))</td>
<td>PHENobarbital (Luminal(^9))</td>
<td>prochlorperazaine (Compazine(^9))</td>
<td>haloperidol (Haldol(^9))</td>
<td>clonazePAM (KlonoPIN(^9))</td>
</tr>
<tr>
<td>ibuprofen (Motrin(^9))</td>
<td>valproic acid (Depakene(^9))</td>
<td>promethazine (Phenergan(^9))</td>
<td></td>
<td>diazePam (Diastat(^9))</td>
</tr>
<tr>
<td>methadone (Dolophone(^9))</td>
<td></td>
<td></td>
<td></td>
<td>LORazepam (Ativan(^9))</td>
</tr>
<tr>
<td>morphine (MSIR, MSContin(^9))</td>
<td></td>
<td></td>
<td></td>
<td>midazolam (Versed(^9))</td>
</tr>
<tr>
<td>naproxen (Naprosyn(^9))</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>oxyCODONE (Roxicodone(^9))</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Nasal Route of Administration\(^1\)

The application of medications to the nasal mucosal surface bypasses first-pass metabolism and allows for rapid and usually painless absorption via the olfactory neurons, supporting cells, and capillary beds resulting in rapid onset of central nervous system (CNS) effects.\(^2\) Due to rapidity of onset, this can be an effective route of administration for rapid relief of seizure activity and breakthrough pain.\(^2\)

The nasal cavity can only hold a small volume of approximately 0.1 mL per nare, therefore a concentrated solution may be needed to achieve an adequate dose.\(^10\) To maximize absorptive surface area, doses should be divided and half of the dose delivered in each nare.\(^11\) Atomizing medications provides a thin layer of medication to the nasal mucosa preventing medication drainage to the oropharynx and therefore allows for better absorption than nasal drops.\(^11\) Irritation of the nasal mucosa may occur if the solution is more basic or acidic than typical nasal secretions, pH 5 to 7, or if the solution is not isotonic.

Table 6. Nasal Administration of Medications\(^1\)

<table>
<thead>
<tr>
<th>Bulb Syringe(^12)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Position child on his or her back. Swaddle or have another person assist with holding the child still.</td>
<td></td>
</tr>
<tr>
<td>2. Before inserting the bulb syringe into the nostril, depress the bulb to expel air.</td>
<td></td>
</tr>
<tr>
<td>3. Place the tip of the bulb syringe into the nostril until sealed. Occlude other nostril.</td>
<td></td>
</tr>
<tr>
<td>4. Slowly release bulb to provide suction of mucus from the nose.</td>
<td></td>
</tr>
<tr>
<td>5. Remove bulb syringe from nostril and squeeze mucus into a tissue.</td>
<td></td>
</tr>
<tr>
<td>6. Repeat suctioning of opposite nostril if necessary.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spray Bottles/ Multi-Dose Counting Bottles/ Unit-Dose Devices(^13)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Prime or shake medication as directed.</td>
<td></td>
</tr>
<tr>
<td>2. Keep head and bottle in the upright position (some unit-dose devices may not need to remain upright and allow for alternative head positioning).</td>
<td></td>
</tr>
<tr>
<td>3. Insert applicator tip into the nostril and close off opposite nostril.</td>
<td></td>
</tr>
<tr>
<td>4. While breathing in through nose, activate medication spray.</td>
<td></td>
</tr>
<tr>
<td>5. Repeat in opposite nostril if necessary.</td>
<td></td>
</tr>
</tbody>
</table>
Medicine Dropper/Standard Syringe with Nasal Atomizer

1. Prepare appropriate dose of medication in the dropper or syringe.
2. Position patient in one of the following positions (if using an atomizer or drops for seizure, administer medication regardless of positioning).
   a. Lying head back – Lying in supine position with head just off the bed in hyperextension.
   b. Lateral head low – Lying on the side with side of the head resting on the bed. Administer medication in the lower nostril.
   c. Head down and forward – Kneeling down with top of the head on the ground with the forehead close to the knees and nostrils facing up.
3. Insert applicator tip into the nostril and administer medication.
4. Repeat in opposite nostril if necessary.

Evidence suggests that midazolam (Versed®) and lorazepam (Ativan®) are both absorbed to therapeutic levels via the intranasal route of administration. The quick onset of action of 5-10 minutes is ideal for management of acute seizures. Some analgesics may be effective when administered intranasally, including fentaNYL (Lazanda®) and ketamine (Ketalar®).

Topical Route of Administration

Absorption of topically-applied medications depends on site of application, thickness and integrity of the skin, blood flow to the skin, body temperature, and drug characteristics. Areas of thicker skin, decreased blood circulation, or decreased subcutaneous fat (depending on drug characteristics) may decrease drug absorption. For example, application of a drug to the mucous membranes with rich blood supply and thin mucosa will lead to increased absorption. Skin thickness varies with age, but is typically thinner in children; therefore, increasing absorption, as well as risk of toxicity. Blood flow to the skin varies with age and is often increased in children; which may increase absorption, as well as risk of toxicity. At the end of life, blood flow may decrease, decreasing the effectiveness. Additionally, children have larger body surface areas which can increase the risk of toxicity when agents intended for local effects are used on large portions of the body or absorption is increased by occlusion of an area, such as by a diaper, or by application to broken skin.

Table 7. Topical Administration of Medications

- Administration technique varies depending on the medication formulation and site of administration. Always consult the package labeling and a pharmacist.
- Caregivers should wear gloves when applying creams, ointments, or gels and wash hands thoroughly after contact with topical medications, including patches.
- Avoid contact with heat sources to the area where topical patches are applied (heating pads, electric blankets, hot tubs, etc.).
- Creams, ointments, and gels should not be applied to broken skin or covered with diapers or other dressings unless directed.
- Patches should not be cut or manipulated in any way unless directed.
- Always ensure that topical patches are disposed of properly, as accidental overdoses can occur with discarded patches.
  - FentaNYL (Duragesic®) patches should be folded with adhesive sides together and flushed down the toilet.

Summary

Pediatric medication administration is a challenging task for many parents, caregivers, and healthcare providers as the majority of commercially–available medications are not formulated for the routes of administration, dosing, and taste preferences specific to pediatric patients. This leads to various manipulations of adult dosage forms and increases the risk for dosing errors and toxicity. As swallowing ability declines, proactively considering alternative routes of administration is imperative. Numerous medications can be administered via alternative routes of administration with rapid absorption and convenience.
References:


Fatigue is a common symptom in children with serious illness and in those approaching end of life. In fact, it may be the most common symptom with 95% of parents reporting fatigue in their children and nearly 60% of parents reporting fatigue leading to suffering in their child at end of life. Although fatigue can be expected as illness severity worsens and as children die, suffering and stress associated with fatigue can often be avoided. Through case vignettes, this article explores the multifactorial nature of fatigue in seriously-ill children, assessment strategies, and effective treatment options.

Fatigue is Multifactorial

Case 1: Adam was born with a rare chromosomal rearrangement resulting in cognitive impairment, developmental delay, seizures, feeding intolerance and recurrent bowel obstructions. Adam was a very happy baby and loved being with his family and playing with his sibling. When he was 4-years-old, Adam’s bowel was partially removed and he required permanent intravenous access to stay hydrated and for his nutrition. Unfortunately, this lead to recurrent line infections and Adam was in the hospital often. His family struggled with how best to take care of Adam and what was important to his quality of life. When Adam turned 6-years-old, he was admitted for a fourth time that year with a line infection. He was much more sleepy and difficult to arouse even once his infection was treated. He no longer smiled or interacted with his siblings. His family felt that this increased fatigue had been worsening over the past 6 months. After an extensive workup which included looking for seizures, pain sources, metabolic changes, medication issues and any other changes, it was determined that this was likely the progression of Adam’s disease. His family felt strongly that keeping Adam home was most important and plans were made for them to be supported by hospice.

Fatigue is often multifaceted and has various sources related to disease, treatment, comorbidities, and associated symptoms. Fatigue can present in children as physical weakness, somnolence, depression,
and inattention. Often fatigue interferes with functioning and causes distress. Fatigue can be distinguished from feeling “tired” by its causes. Feeling tired is usually not related to illness, is often predictable, and typically responds to sleep. On the other hand, fatigue is often pervasive and unresponsive to getting more sleep.

Fatigue in children is most often disease-related or related to the effects of disease-directed treatments. Not only do medications for many illnesses and symptoms cause fatigue (e.g., chemotherapy, opioids, anti-epileptics; see Box 2), but often the underlying disease (e.g., cystic fibrosis, pulmonary hypertension, infection) is also a major contributor. Comorbid conditions such as heart disease, lung disease, malnutrition, mobility limitations, or anemia can also contribute. Furthermore, associated symptoms such as pain, nausea, and dyspnea can add to fatigue symptoms. Approximately 70% of children with pain, 80% of children with anxiety, and 90% of teenagers with depression also report experiencing sleep disturbances. Certain psychological states such as anxiety, depression, sadness, fear, and loneliness can also greatly impact a child’s general wellbeing and level of fatigue. The inter-relation of these symptoms and their association with fatigue is shown in Figure 1.

**Box 2: Common Medications Given to Children with Serious Illness That Can Cause Fatigue**

- Antipsychotics
- Anti-epileptics
- Opioids
- Anxiolytics
- Chemotherapeutics

Children who are undergoing medical treatment can also experience fatigue from the many procedures, frequent clinic visits, and recurrent hospitalizations that are often involved in their treatment. Children may also have limited sleep in the hospital where assessments are happening around-the-clock and there is little time for privacy and rest. In fact, hospitalization in children decreases sleep by 25% and by nearly 50% in children in the intensive care unit. Children with complex medical conditions may have >8 subspecialty providers, making trips to the medical facility a common occurrence.

Sleep disturbances are another cause of fatigue in children.

Common sleep disorders in children, including insomnia and parasomnias (e.g., sleep walking, night terrors) can also be present in the seriously-ill child. These occur often with 25% of children 1-2 years old waking at night, 10-15% of teenagers having trouble falling asleep and 30% of young adults reporting that they do not get enough sleep at least one night per week. At end of life, children may experience profound disengagement and fade in and out of consciousness similar to adults. This can be distressing to caregivers, or may provide comfort to family members as death approaches.

Identifying the causes of fatigue can be challenging in seriously-ill children. As in Adam’s case, fatigue is often multifactorial and caused by an underlying disease, comorbid conditions, medications, and changing disease status. From a pediatric palliative care perspective, families and other medical providers may want to look for any potential causes of fatigue before determining that the major cause is disease progression. Palliative care teams can support families by helping them to articulate what quality of life means for their child and for their family. Often establishing care goals that maximize quality of life can help to refine medical evaluations for fatigue and focus care on what is most important.
Assessing for Fatigue

Case 2: Denah was diagnosed with high-risk leukemia a few weeks before her 16th birthday. Her treatment was long, difficult, and took her away from many of the activities she loved such as cheerleading, swimming, and spending time with her friends. Her leukemia relapsed many times and she was transferred to an academic hospital a few hours away from her home for a Phase I experimental therapy. During this hospitalization, she reported diffuse whole body pain, debilitating nausea that prevented her from eating, and difficulty sleeping. She was started on strong pain medications and tube feedings. She withdrew from care providers and her family. She slept most of time and told those who cared for her that she was “really tired” and to “leave her alone.” She occasionally participated in art therapy or would walk around the hospital unit. Most of the time she was alone and refused to communicate about her symptoms, distress, or suffering.

Expressions and fatigue in children depend on developmental stage. Young children often report the physical sense of fatigue, such as “I can’t run or go play with my friends.” They may keep to themselves or become quieter. On the other hand, young adults often express the psychological aspects of fatigue—especially as they impact a teenager’s quality of life and routine. They may be better able to speak directly to what is causing their fatigue and what treatments make their fatigue worse than younger children. Because of the psychological manifestations, engaging young adults in a discussion about their fatigue may be challenging and determining how symptoms are related to underlying anxiety or depression is important.

Assessment for fatigue often begins with an assessment of symptoms, including sleep history. History and physical exam are critically important including checking for bedtime issues, bedtime routine, excessive daytime sleepiness, awakening at night, typical sleep duration patterns, and snoring. Asking young adults or parents of children <12-years-old to complete a sleep diary for one week may be helpful. These diaries can be evaluated for fatigue onset, type, aggravating/alleviating factors, and impact on functioning. Fatigue can also be assessed and monitored using fatigue scales. The Childhood Fatigue Scale can be used for children ages 7-12 years and the Fatigue Scale Adolescent for children and young adults ages 13-18 years.4,5 A simple numeric scale and the Parent Fatigue Scale can also be used.6 As mentioned previously, careful attention to other contributing symptoms, medications, and treatments remains important.

Depending on the child’s underlying condition and disease trajectory, a sleep study (also called a polysomnograph) may be indicated. A sleep study evaluates for contributors to poor sleep such as seizures, apnea/airway obstruction, gastroesophageal reflux, and muscle movements. In children who have serious illness, the cause of fatigue can be difficult to pinpoint and often there are many contributing factors. As children approach end of life, the opportunities and the importance of testing for a specific cause may be less crucial. Treatment can be started empirically and monitored for results. In Denah’s case, her fatigue was multifactorial and required the help of many of her care providers to evaluate and treat. This included the help of family, social workers, psychologists, psychiatrists, and palliative medicine as an additional layer of support to her oncology team.

Treatment for Fatigue

Case 3: Jenny was a 20-year-old female with a history of anxiety and osteosarcoma. At the time of diagnosis, she underwent chemotherapy and an above-the-knee amputation. She subsequently struggled with phantom limb pain and persistent neuropathic pain. Upon reimaging, Jenny was found to have multiple metastases throughout her lungs. She was started on immunotherapy with no response and subsequently received radiation. About 3 months prior to her death, she was admitted for increased pain and shortness of breath and transferred to the ICU for increased respiratory support. Her pain was severe and she received high dose opioids. She also received spiritual care support, family counseling from a social worker, and further opportunity to discuss goals of care. She was discharged home with hospice supports, but continued to struggle with pain management and fatigue. In addition to her pain medications, she
was started on a stimulant to take in the morning and midday. Although this medication was rapidly titrated, she continued to have significant fatigue, which led to her limiting her pain medication use and resulted in two pain crises. She worked with hospice to change the timing of her medications, which helped, and as she approached the end of life her fatigue became less burdensome. She was able to attend a party thrown by friends. Over the final two weeks of her life, she wanted to go out less and focused her energy inward. She died peacefully in her sleep at home surrounded by her family.

The management of fatigue often takes time and a trial-and-error approach. For fatigue and any related sleep disturbance, changes should be tracked and monitored over time. This can be done by assessing and recording changes with each visit or by keeping track of daily symptoms. Young adults may feel empowered by this engagement in their medical care. By monitoring changes and effective treatments, any outstanding issues can be identified.

A multidisciplinary approach to the treatment of fatigue is critical. For seriously-ill children, fatigue can have significant psychosocial and emotional components. Social workers, spiritual care providers, and grief/loss counselors can address many of these contributing issues. Nurses and physicians can provide interventions specifically targeting the symptom of fatigue, or addressing related symptoms and suffering. In addition to the direct treatment of fatigue, management can also include an evaluation of comorbid conditions contributing to fatigue. If treatments are making fatigue and sleep worse, it may be worth considering if they should be discontinued if the goal is comfort (e.g., diuretics, steroids, non-invasive ventilator support leading to agitation, or frequent suctioning overnight). Non-pharmacologic treatment for fatigue as children approach end of life can also include decreasing the frequency or number of oral medications, in particular those that may impair sleep or are given at a time where the child is normally resting. Often using longer-acting medications to manage symptoms overnight to limit sleep interruptions can be helpful.

Decreasing monitoring (e.g., blood pressure and temperature checks, arterial lines) and focusing on how the child looks, feels, and acts may also help with fatigue management.

Encouraging age-appropriate sleep routines can also be helpful. These include consistent timing of bedtime/waketime, and addressing toys, lighting, and co-sleeping with families. Communicating this routine to hospital staff is valuable so that inpatient stays limit the interruption of these important processes. These aspects of sleep hygiene may naturally change as a child becomes more ill and focusing on what is distressing and causing suffering becomes most important.

Families should receive anticipatory guidance on the fluctuating nature of sleep and fatigue as a child nears death.

Other interventions that can be helpful for fatigue include cognitive behavioral therapy, massage, acupuncture, aromatherapy, and hypnosis. A complete list can be found in Box 3. Although many of these techniques have not been studied specifically as they relate to fatigue and/or in children, they often provide comfort and support around symptoms of fatigue when they are present.

Pharmacologic treatments for fatigue are also often used. Although there are no medications that are approved by the FDA for sleep in children, many of the medications used for other symptoms can be helpful. Often comorbid symptoms, such as insomnia, seizures, itching, and nausea help to guide

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**Box 3: Non-Pharmacologic Treatments for Fatigue**

- Make a schedule
- Plan important activities during times when the child has the most energy
- Do a little, often
- Short naps
- Walking/regular exercise
- Eating balanced meals
- Increasing/decreasing visitors
- Fun activities to engage the child and/or for distraction
- Hot baths
- Increasing control of care
- Maintaining sleep hygiene
- Limiting caffeine, fluids, and television/screen time in the evening
- TENS (transcutaneous elective nerve stimulation)
- Massage
- CBT (cognitive behavioral therapy)
- Stress management
- Guided imagery
- Listening to concerns about fatigue
treatment as some medications can be used to address multiple symptoms simultaneously. When fatigue is causing suffering, treating the most likely underlying cause and any other prominent symptoms can be a good place to start. Table 1 lists common medications used to help with fatigue and their indications.

In Jenny’s case, fatigue was often her most bothersome symptom and medication timing and dosing were all considered. She was started on a stimulant medication but this did not seem to provide the desired benefit. Psychosocial and emotional support, along with legacy building, was provided by family, social work, palliative care, and hospice teams and was the most successful in addressing her fatigue. Careful and close follow up was paramount to addressing the many aspects of Jenny’s fatigue. Ultimately, her fatigue became less distressing towards the end of her life.

**Conclusion**

Fatigue is a common symptom in children with serious illness and those approaching end of life. Assessing for comorbid conditions, contributing symptoms, and medication side effects is critical. Often fatigue is multifactorial and symptoms need to be assessed, tracked, and managed overtime. Successful treatment often involves a multidisciplinary team and non-pharmacologic, as well as pharmacologic, treatments.

**References:**


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| Table 1: Common Medications Used to Treat Fatigue in Children |
|---------------------------------|---------------------------------|
| Medication Class | Indication/Comorbid Symptoms |
| Stimulants | • Fatigue as side effect from other medications or due to disease progression |
| • Caffeine | |
| • Methylphenidate | |
| • Modafinil | |
| Herbal | • Brain anomaly or time change |
| • Melatonin | |
| Benzodiazepines | • Nausea |
| • Lorazepam | • Seizures and parasomnias |
| • Clonazepam | • Seizures and muscle spasms |
| • Diazepam | |
| Opioids | • Cough, dyspnea or severe pain |
| • Morphine/Hydromorphone/Methadone | |
| Adjuvant Analgesics | • Neuropathic pain |
| • Gabapentin | • Neuropathic pain |
| • Duloxetine/Venlafaxine | • Neuropathic pain and sedating |
| • Amitryptyline/Nortryptiline | |
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UNDERSTANDING SILENCE: SYMPTOM MANAGEMENT IN CHILDREN WHO ARE SEVERELY DELAYED AND/OR DIAGNOSED WITH DISORDERS OF CONSCIOUSNESS

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In front of me sits a tray of phlebotomy tubes, needles, a tourniquet, alcohol swabs, and Band-Aids depicting every “character” that a typical child’s eye might light up at the sight of: Doc McStuffins, Olaf, Spiderman, you name it, we have it. And let’s not overlook the phlebotomist who is already scouring over the child’s arms, legs, hands, and feet for any sign or flash of blue. A pretty typical phlebotomy scene, however, our patient is anything but your typical child getting a blood draw. She is lying supine in a wheelchair that was custom made to fit her contorted body, her arms bent at unusual angles, and I’m told from her chart, that she is in a persistent vegetative state. She is one of 137 medically fragile children whom I see on a daily basis for procedural preparation, support, and psychosocial care. This is pediatric long-term care, each of these children call our hospital their “home.” They are dependent on wheelchairs, ventilators, feeding tubes, tracheostomies, and on each person who cares for them, to function, play, and live in this world. Most cannot even tell their caregivers they have an itch, let alone scratch it. How tempting it is to glance at these kiddos and think that their symptoms are minimal, particularly due to their inability to communicate them. These children are certainly not squeaky wheels. However, a closer look reveals that each of these children has symptoms that benefit enormously from effective symptom management.

As their child life specialist, I’m continually tasked with the challenge of managing symptoms in a population that cannot communicate with words, advocate for their needs, or even play like a typical child can and does. So how then does one feel as though they are managing pain, reducing anxiety, or helping a child in this state function as typically as possible? Turns out, each of these spectacular kiddos have something to say after all, as long as there is someone there to listen, ever so carefully.

Persistent vegetative state (PVS), or the new name, unresponsive wakefulness syndrome (UWS), proposed back in 2010 (Laureys et al., 2010), is defined as the patient having preserved sleep-wake cycles, respiration, digestion, or thermoregulation, but remaining unaware of themselves or their environment (Laureys, Owen & Schiff, 2004). On the other hand, to be considered in a minimally conscious state (MCS) one must “show limited but clearly discernible evidence of consciousness of self or environment, on a reproducible or sustained basis, by at least one of the following behaviors: (1) following simple commands, (2) gestural or verbal yes/no response (regardless of accuracy), (3) intelligible verbalization, (4) purposeful behavior (including movements or affective behavior that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity)”(Giacino et al., 2002).

Other altered states of consciousness that make up disorders of consciousness as a cohort are brain death, coma, and locked-in syndrome, each with its own definition and set of criteria. What is most fascinating about working with children who have been diagnosed with a disorder of consciousness is that most of the literature available is based on the study of adults. Because of this, many of the available measures of consciousness are not appropriate for a pediatric population. In particular, measurements that involve the presumed acquisition of language may not be appropriate for children who were born with severe disabilities and therefore a disorder of consciousness. How can we base a child’s assessment of consciousness on their response to questions asked, if we have no actual proof that the child ever acquired language in the first place? All this points to the extreme complexity of trying to determine what level of pain and/or anxiety a child with a disorder of consciousness is feeling and what level of support he or she needs to match this. As a result, our symptom management with this population ends up relying heavily on assumption. The ethical thing for any clinician to do is to assume that the child both feels and
manifests pain and anxiety and treat accordingly. In the work of the child life specialist, this means always providing preparation, support, and distraction for every patient despite their ability to let us know if this support is wanted or needed. Far better to have supported a patient who may have been anxious than to have offered no support to a patient who needed it but could not ask for help.

What does that support look like? How do we effectively help a child cope who cannot communicate to us what exactly is hurting them, or what they are anxious about? As we wander back to the phlebotomy suite in the scene first described earlier, the interventions for symptom management may look something like this:

**Communication is not always verbal:**

Tell each child what they will hear, smell, feel, see, or taste. This is a five senses approach. At times, it may even be helpful to expose them to stimuli (the smell of an alcohol pad) prior to the procedure taking place. This will desensitize the child to the sensory components of the procedure. A great example of this is working with this population of children during dental clinics. A routine dental visit for a child in a minimally conscious state is anything but routine. Often, seizure medications, secretions, lack of oral feeding, and lack of tolerance of oral care can leave the teeth with layers of built up calculus and plaque, swollen gums, and misaligned teeth. Many children are orally defensive and chomp down or pull away from any stimuli on the mouth area. We have found that a ten-minute oral massage prior to going in to see the dentist helps slowly introduce the child to the concept that there will soon be someone prodding his or her mouth. We believe this sends a “warm-up” signal to the brain that says “hey, something is going to be happening here, so let’s get ready.” By starting with a gentle massage, children may feel less anxious and defensive when we move onto a more aggressive oral cleaning. Other easy interventions for symptom management may include utilizing a pair of sunglasses to block out the bright dental light that some children who have the inability to control their eye dilation may find extremely uncomfortable or painful. When time to prepare a child is taken, we see clear benefits to the child. Signs of distress are minimized (oxygen saturations go up or remain steady, heart rate stays down, and the child’s facial affect is pleasant or unchanged). These are the signs that tell us the intervention has helped minimize the typical discomfort we may see.

**Distraction or refocusing:**

Another way to help children calm their anxiety during procedures is to employ distraction or refocusing. We started off utilizing the Buzzy device for immunizations and venipunctures due to its proven effectiveness in studies (Baxter, Cohen, McElvery, Lawson, & von Baeyer, 2011), but quickly found the distractive nature of the vibration so helpful with this population that we use it during almost all procedures including dental visits and trach changes. The Buzzy device, developed by a pediatrician, works on the gate theory of pain.

“Gate control” is the term used to describe pain relief by causing sensations other than pain, and then sending them down the same pathway where pain gets blocked at the “gate”… A single summary signal is then transmitted up the spinal cord, thus excess vibration or cold can overwhelm or dilute the sharp pain from shots, itching, or burning from medications.

Using the body’s own nervous system, the gate control theory invokes the concept that the final common pathway for sharp pain to the brain can be shut out by the nerves that transmit cold and vibration senses. Just as running a burn under cold water stops the sharp pain, or rubbing a bumped elbow stops the pain, simultaneously stimulating vibration and cold receptors can dull or eliminate pain” (Baxter, A. (n.d) Gate theory of pain. Retrieved from: https://buzzyhelps.com/research/gate-control-theory).

Utilizing the Buzzy in patients who are minimally conscious or severely delayed seems to have a similar effect with the additional benefit of providing relaxation and distraction. Other more traditional methods of
distraction also can help with this population; pinwheels, bubbles, and light spinners all serve their purpose in momentarily distracting the child’s focus away from the procedure and pain.

Environmental child life:

Children who are in low-awareness states may find loud sounds, bright lights, or many voices speaking simultaneously confusing and frightening especially when they already struggle to process their environment. A technique we often utilize during procedures is to attempt to control the environment the child is in, in order to promote healing and relaxation. Utilizing the ONE VOICE 4 Kids (n. d.) technique, rhythmic speech, or low shushing sounds close to the ear allows the child to refocus on the relaxing sounds. Additionally, relaxation music can change the environment of the procedure and often vicariously helps staff relax. If done in conjunction with a Music Therapist that can provide live music, this can show a visible effect on the child and even the staff. Often, simply by relaxing the staff, we vicariously allow the child to become more relaxed. Having a spa-like quality to the room in which a procedure is done will of course affect how the child perceives his or her current situation.

Presuming competence:

One of the biggest mistakes we make as health care providers to a population that has difficulty communicating is assuming they cannot understand what is being said and/or done around them. Often, we simply do not have enough information to evaluate whether or not this is true. Because of this, the converse should always be the standard. Every healthcare professional should enter every patient relationship assuming that the child can and will understand everything that is being said and done. The simple truth in this is, no harm will be done if we assume the latter, but presuming incompetence and not adequately preparing the child can cause undue fear and anxiety that could easily be prevented. Presuming competence is perhaps the easiest way to control symptoms in children who are severely impaired or have disorders of consciousness.

Each of these interventions, taken together work tremendously well in managing pain and anxiety in children who have been diagnosed with a disorder of consciousness. Revisiting our patient getting a venipuncture, as she lies there, we dim the lights (using only a smaller light for the phlebotomist), turn on gentle relaxing piano music with undertones of ocean waves, and begin speaking to her in a slow, hypnotic voice. “Sophie, you are visiting the phlebotomist, she is looking at your arms trying to find the best place to draw your blood.” Perhaps at this point we also will introduce the gentle vibration of the Buzzy. As the phlebotomist cleans the site we may say “Sophie, you are now feeling the alcohol swab clean your arm. Some children tell me it feels a little cold.” We continue to narrate the procedure perhaps while alternately humming to the music or providing a gentle shushing in Sophie’s ear, lulling her into an almost trance-like state. We notice that instead of seeing her heart rate spike at the pinch of the needle, it remains steady. As Sophie’s stats remain stable and we withdraw the needle, it can be assumed that with careful attunement to her unique needs, we have indeed communicated and successfully managed her symptoms despite her inability to verbally indicate to us her potential anxiety, fear, pain, or discomfort.

We are ethically bound as health care practitioners to provide symptom and pain management to each individual in our care. Children who are extremely disabled and/or non-verbal, and their families, are often overlooked because of the difficulty in identifying their sometimes invisible, but prevalent, symptoms. However, when symptoms are successfully managed the results are minimized stress and enhanced quality of life for each child we encounter.
References:


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EXISTENTIAL PAIN IN CHILDREN AND TEENS

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Part I: Children and Teen’s Existential Pain and A Theory of Helping Children Give Voice to their Knowledge

Zoe is a three-year-old girl with a neuroblastoma. By the time of her diagnosis, the cancer had already spread to her lymph nodes and her parents and care team decided to focus on palliative care and improving her quality of life. Zoe’s hospital room overflowed with dolls and stuffed animals. She liked to sing along with one that played the song, “Jesus loves me,” when you squeeze it. Zoe’s dad confided that when his daughter went for her biopsy, she held her blankie that Grandma had made her, and when she woke up she says that she saw Grandma. Her dad looked away, wiped a tear, cleared his throat, and said, “I can’t speak to her about it.”

Zoe’s mom felt distressed. She knew that Zoe was dying, but felt at a loss for how to talk with her about it. She agonized over wondering if Zoe knew that she was dying and if she even knew what dying meant. Zoe’s mom felt paralyzed by a fear that she would emotionally harm her by bringing up the topic of death. She worried that Zoe felt isolated and scared.

A fundamental difficulty in caring for a child with existential pain is the age-old challenge of knowing and understanding what the child is thinking and experiencing. Understanding children’s existential pain requires approaching them and their pain within the context of relationship. Cognitive psychologist Jean Piaget articulated the risk that adults, whether they are researchers, caregivers, teachers, or parents, have when working with children of inadvertently imposing their worldview on the child.

Zoe’s mother was aware of this risk, and, without feeling equipped to engage her, she felt at a loss, which created a strain in her parent-child relationship and exacerbates her own existential pain. The same can be true when caregivers feel at a loss for understanding and how to engage.

Caring for the child’s or teen’s existential pain begins with seeking to understand the experience of pain within the family system. A significant aspect of Zoe’s parents’ response to her was their own existential suffering. A significant clue to Zoe’s coping with her situation is her attachment to her blankie. Object Relations founder and theorist, Alfred Winnicott, named the literal and physical space between caregiver (mother) and child (infant) as transitional space: “The gap between mother and infant is an external reality that is matched by an expanding internal space inside the infant in which he or she begins to grow and to think, really to become a person.” Winnicott recognized the creative potential in transitional space. Within the transitional space, Winnicott described infants developing transitional objects in order to cope with separation, loss, and frustration and emphasized that each individual uniquely creates transitional objects. Zoe’s attachment to her blankie was an indication that she had developed it as a transitional object that would be helpful in general in coping with frustration and separation from her parents and also during the added frustrations she was experiencing in illness.

A nurse imagined that Zoe’s father was heart-broken by seeing his child go into surgery and that this brought his tears and stifled his voice. The nurse, however, gently asked Zoe’s dad what was so painful about hearing about Zoe’s connection with her Grandma. She learned that Zoe’s grandmother, her father’s mother, had died two years previously and that he “hadn’t gotten over it.” Zoe’s dad’s coping with his daughter’s illness and inevitable death was strained by his on-going grief for his mother. As Zoe’s dad

received more care for himself, he was better able to support Zoe. The nurse demonstrated her willingness not to assume she understood Zoe’s father and approached him with curiosity. Zoe’s father was more able to care for Zoe as he received care himself and mustered more courage to be with her during this harrowing time in their lives.

Part II: Being a Midwife for Knowledge

Daniel was 15 years old when his heart transplant began to fail. Born to a single mother who grew up in Communist Russia, Daniel had become a Born Again Christian at the age of 12. He requested to speak with a Chaplain because he was worried “about his mother’s soul,” that she would not go to Heaven and he would not see her in the afterlife.

Existential pain can be known or it can hover below the surface of consciousness or be buried deep in one’s psyche. Once caregivers become comfortable (or comfortable enough) with their own limited knowledge of the other and begin to access their own curiosity, they can recognize that people stand on the edge of the unknown with even their own self-knowledge. The renowned developmental psychologist, Carol Gilligan, has helped us understand that the existential crisis of censoring one’s knowledge begins during childhood. In a study of school girls, Gilligan and colleagues discovered the process of self-censoring takes place during the early teens, during which confidence, outspokenness, and clarity give way to doubt and tentativeness. Gilligan saw an exponential increase in the girls’ use of the phrase, “I don’t know,” between the ages of eleven and sixteen. As Gilligan explained, “They start not knowing what they had known.”

Gilligan later noted a significant time of initiation into male identity for boys during the ages of five and seven, when boys begin to be expected to “act like real boys” and thus begin to unknow their own emotional knowledge.

While existential pain is often understood as the raising of distressing questions (such as, “Why do bad things happen to good people like me?”) or to giving discomforting explanations for one’s suffering (such as, “I must be being punished because I am a bad person”), it can also be the alienation of oneself from one’s own knowledge. A fundamental aspect of care is to not pressure children to not know what they know. A second aspect is to help them discover the knowledge they are in the process of developing. Gilligan’s understanding of the suppression of knowledge can lead to an understanding of the role of chaplain, or spiritual caregiver, or anyone seeking to care for a person with existential pain. This existential care giver is one who helps others remember; or, as Plato famously characterized Socrates, as the midwife to the soul. Socrates encounters his student Theaetetus who is frustrated with his learning process and state of knowledge; he “cannot shake off a feeling of anxiety.” Socrates seeks to console his student, “These are the pangs of labor, my dear Theaetetus, you have something within you which you are bringing to birth.” At which point Socrates reveals himself as the son of a literal midwife and that he himself practices midwifery of knowledge. (Theaetetus,148-9)

The Chaplain-On-Call, a Buddhist priest, responded to Daniel’s urgent request to see a chaplain. Daniel began to realize that what pained him most was worrying how his mother would carry on after he died and how he wanted to talk with her but felt at a loss for how to begin. The Chaplain helped him articulate these troublesome thoughts and feelings. Once his pain was acknowledged, Daniel felt freer to think creatively about how to approach speaking with his mother, as the two of them know each other better than anyone else. Rather than coming in as an authority figure with answers, the Chaplain helped Daniel access his own knowledge and spiritual resources.

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Helping patients give birth to their own knowledge does not obviate addressing their explicit requests. The Chaplain-on-Call made a referral for Daniel to a faith-specific chaplain who could speak with him with authority from within their shared tradition and provide him with pastoral support within the context of their beliefs and practices.

**Part III: When Meaning is Broken**

Julia was a 16-year-old girl with leukemia who received a bone marrow transplant and her 11-year-old sister, Gaby, was the donor. Due to complications, Julia was hospitalized for months after what was supposed to be a routine hospitalization. In addition to the losses of her health, school, a peer group, and junior prom, she was also losing her identity. When the art therapist noticed a piece of artwork on Julia’s table and asked if she had made it, Julia smiled and said, “My sister made it for me”; but then she frowned and added, “I used to be the artist.”

Julia’s illness was challenging the identity she was formulating and the sense of purpose she felt in contributing to others through her artwork. The art therapist helped her become aware of this existential pain that was lurking. Together they decided that the world needed more than one artist and that despite her sister’s talents and abilities, Julia was the sole possessor of her unique voice and vision.

When Julia died, a medical resident overheard Gaby make a side comment about how she was “no good at anything.” Though tempted to immediately reassure her, he compassionately asked her what made her think that. She had developed her own identity and sense of meaning as “the one who would save her sister.” The resident’s family-centered approach helped him know the importance of the sibling experience and recognize Gaby’s own existential pain. Speaking the awful thoughts she was harboring began to release them, opening the possibility for rewriting her sense of purpose.

**Part IV: Existential Healing**

When Zoe’s mother asked the Child Life Specialist how to speak with her daughter about dying, the Child Life Specialist encouraged her by saying, “You know your child the best. How would you talk with your Zoe about anything else?” Her mom knew that as a young child, Zoe needed straightforward and simple questions and statements and often was very concrete. To her surprise, Zoe knew she was dying, even if she didn’t fully comprehend it or its finality. Zoe asked, “Will I see Uncle Eddie?” her mother’s brother who had died as a young child. Zoe had a concrete understanding of the current world and the afterlife. Zoe’s mother told her, “Yes, you will see Uncle Eddie. And you will play together in Heaven.” This brought much comfort to Zoe, and to her parents.

NOTE: All scenarios are composites in order to protect the privacy of individuals.

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Children’s Project on Palliative/Hospice Services
ChiPSS serves as the Pediatric Advisory Council for the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics
Using Reiki Therapy for Symptom Management in Children Receiving Palliative or Hospice Care

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Reiki therapy has been a passion of mine since I first learned the technique in 2005. I was working as a bedside nurse at a large children’s hospital and my manager offered to teach any nurse from our unit that wanted to learn. I was already a massage therapist and knew the value of touch therapies, but did not use massage at the bedside since there are some contraindications and it takes more than a few minutes to achieve results. Reiki therapy, however, is perfect for spontaneous bedside use. I most often used my skills with non-verbal children who could not tell me what was wrong. I found that 5-10 minutes of Reiki therapy would calm an agitated child for several hours without any additional medication.

While my own experience told me that Reiki worked for children, there was no research in the literature in the pediatric population. I decided to complete a PhD in nursing in order to be better qualified to pursue a career in research looking at the effects of Reiki and other complementary therapies with children receiving palliative care. During my dissertation study (detailed below), I had many wonderful experiences during the Reiki sessions with both verbal and non-verbal children. Verbal children had reactions that included feeling better, feeling warm, feeling happier, and feeling nothing. Non-verbal children gave a clear picture from their actions and their physiologic responses, especially during the second visit, that they felt something with Reiki. The response of one non-verbal girl with neurological problems was very interesting. In the first session, she displayed her baseline behavior as she moved continuously (as she did during the recruitment visit), but during the second visit as I was providing Reiki, she laid her head on my arm and was completely still with her eyes open for a full 10 minutes. The face of another young boy with muscular dystrophy lit up when I walked into his room for the second treatment. A third child who was having seizures every few minutes for more than 24 hours prior to my second visit, continued to experience seizures for the first 5 or so minutes of the Reiki session. After that first 5 minutes, he did not have any more seizures for the remainder of the session nor for the time I was in the room after the treatment. Whether it was the Reiki that stopped the seizures or whether the medication finally controlled them or it was a combination of the two is unknown. Providing Reiki to children, watching their expressions change and their pain and agitation decrease is personally satisfying.

The National Center for Complementary and Integrative Health (NCCIH) defines Reiki as a complementary practice wherein practitioners place their hands lightly on or just above a person, in discrete positions, with the goal of facilitating the person’s own healing response (National Center for Complementary and Alternative Medicine, 2006). There are three degrees of Reiki practice: first degree practitioners are able to treat themselves or others through light touch; second degree Reiki expands practice to the use of distance healing; and third degree or master level Reiki expands practice to training others as Reiki practitioners. Typical Reiki therapy sessions last about 30-90 minutes.

Reiki therapy, for those who have not experienced a Reiki session, is a light touch, generally relaxing therapy. Participants in a qualitative study with adults described their experience as “nurturing,” “warm,” and “secure” (Ring, 2009). Bedside nurses and administrators who used self-Reiki during their shift stated that Reiki helped them feel more energized but also relaxed and calm after a self-Reiki session even during a stressful workday (Vitale, 2009).
Evidence from randomized controlled trials (RCTs) with adults show mostly positive results especially in pain, anxiety, and depression. A two-group, waitlist control RCT examining Reiki therapy for pain, anxiety, and depression in 20 community dwelling older adults showed a significant within- and between-group decrease in pain, anxiety, and depression (Richeson, Spross, Lutz, & Peng, 2010). Despite a small sample size, this study was statistically significant. Another randomized, two-group crossover study tested Reiki alternating with rest on cancer patients’ experience of pain, anxiety, and fatigue (Tsang, Carlson, & Olson, 2007). In the Reiki group, pain, anxiety, and fatigue significantly decreased and participants experienced significant improvement in quality of life. In another four-group (Reiki, sham Reiki, progressive muscle relaxation, and no treatment/control) RCT of 120 adults with a history of depression, anxiety, and chronic pain examining pain intensity, depression, state and trait anxiety, self-esteem, and locus of control, between group comparisons were significant for the Reiki group (Dressen & Singg, 1998). In one of the largest studies to date, 207 adults with type 2 diabetes and peripheral neuropathy were randomized into three groups (Reiki, sham Reiki, and usual care). While both the Reiki and the sham Reiki groups had significantly decreased pain and increased walking difference, there were no differences between the two groups (Gillespie, Gillespie, & Stevens, 2007).

Although large children’s hospitals have been offering Reiki to children for years, research in the use of Reiki with children is very recent. The first report that mentions children in the scientific literature was a pilot program that taught parents to use Reiki with their hospitalized children (Kundu, Dolan-Oves, Dimmers, Towle, & Doorenbos, 2013). This program was very successful in that all of the parents that participated felt empowered by their increased role in caring for their child and the children experienced increased relaxation and comfort and decreased pain (Kundu et al., 2013). A case report discussing a young child with a history of perinatal stroke, seizures, and type-I diabetes examined the use of Reiki for seizures, relaxation, and sleep (Bukowski & Berardi, 2014). The child received 20-minute Reiki sessions twice weekly for six weeks. The child reported no seizures during the study period, decreased stress, and increased restful sleep during the study although the mother reported that the child’s sleep pattern returned to baseline after the study ended (Bukowski & Berardi, 2014). Kundu and colleagues (2014) completed a double blind Reiki versus sham Reiki RCT with young children receiving a wide variety of out-patient dental procedures (ranging from cleft palate repairs to dental extractions) under anesthesia. The children received 20-30 minutes of Reiki or sham Reiki in an exam room prior to the procedures. There was no difference in pain scores or post-surgical medication use between the two groups (Kundu, Lin, Oron, & Doorenbos, 2014). However, children in the sham Reiki group received significantly more pain medication during surgery, the length of Reiki/sham Reiki interventions were not standardized, and several children left the hospital before the final pain assessment. A recent study examined adolescents to see if Reiki or cognitive behavioral therapy (CBT) would be more effective in decreasing depression in adolescents when compared to waitlist control (Charkhandeh, Talib, & Hunt, 2016). Results showed that CBT was more effective than Reiki or waitlist control and Reiki was more effective than waitlist control for decreasing depression (Charkhandeh et al., 2016). The authors stated that while CBT was more effective for depression, Reiki might be a good alternative for those adolescents who do not wish to use CBT.

Only one study has been reported involving Reiki therapy with children in palliative care (Thrane, Maurer, Ren, Danford, & Cohen, 2016). A convenience sample of children ages 7-16 was recruited from a palliative care service. Two 24-minute treatments were completed on non-consecutive days within one week in the child’s home. Pre and post measures were completed for each treatment. Pain and anxiety were measured using a visual analog scale and heart and respiratory rates were measured manually. Sixteen children (8 verbal and 8 non-verbal) completed the study. Verbal children self-reported for pain and anxiety while parents reported for non-verbal children. Overall, the children were female (69%) and white (94%); 44% had a cancer diagnosis and the remaining 56% had either a congenital or genetic condition. The verbal children had been with palliative care 1.6 to 22 months while the non-verbal children had been with palliative care 5.4 months to 9.8 years (Thrane et al., 2016). Due to small sample size and a floor effect for pain and anxiety (about half the sample did not have pain or anxiety before the Reiki session), most pre to post measures were not significant. However, clinical effect sizes calculated using Cohen’s d were medium to large demonstrating a clinical effect (Thrane et al., 2016).

There is a slowly growing body of evidence showing mostly positive results for the use of Reiki therapy for symptom management in both adults and children. The majority of reports are from small pilot studies.
with less than 30 participants. Further research is needed, particularly large, fully-powered studies with enough participants to detect whether Reiki made a difference in the outcome variables.

Children and adolescents are accepting of Reiki and most complementary therapies. These therapies often help children cope with painful procedures as well as general symptoms. Reiki therapy is helpful for many symptoms but it is particularly helpful in situations where the child cannot or does not want to actively participate in an intervention such as guided imagery or art therapy. Reiki can be used with children who are too ill to move or even speak, who may be non-verbal, unconscious, or at the end of life. Reiki, because it is a gentle, relaxing, non-invasive touch therapy, can provide comfort during palliative and hospice care.

References:


PALLIATIVE SEDATION FOR INTRACTABLE SUFFERING AT END OF LIFE IN CHILDREN
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Every year in the US, there are close to 19,000 pediatric deaths age 1-19 years, many of them from chronic complex conditions such as malignant, neuromuscular, and cardiovascular conditions. In any given day an estimated 5,000 of these children are in their last 6 months of life. For many, attentive pain and symptom management is successful. But parents report over ¾ of their children “suffered a lot” at end of life especially from pain, fatigue, gastrointestinal issues, and poor appetite. “Houston, we have a problem.” Skilled pediatric palliative care supports excellent pain and symptom management for most children with goals of comfort and optimal interaction. Palliative sedation (PS) addresses a small percent of these whose pain and symptoms are refractory to optimal management and are causing intolerable suffering. Unfortunately, there are few data describing the number of cases per year and appropriate guidelines for palliative sedation in children and adolescents. Much of the experience and many of the recommendations are based on adults.

What is palliative sedation? PS is management that limits the child’s awareness of suffering that is intolerable and intractable with the goal of relieving symptoms and suffering to a level acceptable to the child/adolescent. Some refer to a specific level of consciousness, but this is not the goal. Altered level of consciousness including unconsciousness is a likely consequence of relief of suffering offered by PS.

• How do we tell that the pain (or symptom) is intolerable? In addition to standardized scales, we seek the input of the child, with supportive input from the parents/caregivers. We do not rely on the parent input alone if the child has the capacity to communicate with us. While we acknowledge that the parents are suffering as well, our primary duty is to treat the child.

• How do we know that the pain/symptom is intractable? The providers should be convinced that all available treatments at appropriate doses likely to be effective with acceptable side effects, and available within a reasonable time frame, have been attempted. This requires the input of providers highly skilled in pediatric pain and symptom management, such as those with certification and/or training in pediatric palliative care. If such expertise is not available, consider transfer of the child to a tertiary children’s center with pediatric palliative care providers.

• What assessment should be included?
  o What is the symptom and signs?
  o Have all contributing sources of distress been addressed?
  o For whom is the symptom distressing?
  o How does the child perceive the symptom and what are his/her goals and preferences?
  o What are parents/caregivers’ preferences and ability to tolerate the child’s distress?
  o What approaches and treatments have been fully explored at optimal doses and with acceptable side effects?
  o What is the endpoint? How will we know that suffering is relieved?

• What are the criteria for use?
  o Truly intractable symptoms, intolerable pain/suffering
  o Incurable illness/disease
  o Imminent death
  o Expert consultation such as pain team, palliative care team, bioethics committee
Informed consent
- Documentation, transparency, data collection

What are the barriers to optimal pain and symptom management including palliative sedation?
- Inadequate supply of nurses, physicians, pharmacists trained in pharmacologic and nonpharmacologic management of pediatric pain and symptoms
- Few available multidisciplinary teams such as oncology, pediatric palliative care, and pain management
- Symptom assessment tools that are unavailable or not used
- Logistical challenges in getting rapid assessment, orders, and delivery of medications
- Fear of escalating opioid doses
- Delayed parental acceptance that hope for cure is no longer realistic
- Lack of understanding about palliative care in general, triggers for pediatric palliative care consultation, and palliative sedation specifically
- Fear of euthanasia (intentionally hasten death) and lack of understanding of the ethical principles underlying the decision, especially the “double effect”
- Lack of institutional PS guideline

What is the setting? While this may be done at home with adequate support (less frequently available in the US than in Europe), PS is generally provided in the pediatric ICU or hospital setting.

What is the timing? PS is provided when death is “imminent.” It is important to include the child/adolescent in the decision about timing of initiation of PS. As with adults, the child or adolescent may have things to accomplish or finish up prior to death. In case of intractable suffering, PS is usually offered as an option in the last days of life and up to 2 weeks before expected death. One of the rationales for this timing is that it supports the notion that death is due to the underlying disease/condition not the PS and associated decreased intake. Artificial nutrition and hydration are frequently withheld/withdrawn at end of life as they may contribute to GI and respiratory distress, and it is unlikely that death from dehydration will occur in less than two weeks. In adults treated with PS in the last 2 weeks of life, there is little difference in life span with and without withholding/withdrawing artificial nutrition and hydration. In fact, in adults being treated by the palliative care team, there is little difference in survival between those sedated or not sedated. Palliative sedation for existential suffering or when the patient’s death is not imminent remains very controversial.

What about other life-prolonging treatments? Decisions to initiate PS and decisions to stop other management directed at prolonging life are separate. If death is imminent, it is likely that artificial ventilation and other medications and treatments directed to a goal of prolonging life, but not contributing to the child’s comfort, are no longer beneficial and can be weaned and stopped. This will likely include artificial nutrition and hydration. In any case, children at end of life eat and drink very little. It is usually appropriate to continue opioids and other symptom-directed treatment that are providing comfort with acceptable side effects. It is recommended that a “do not attempt resuscitation” or “allow natural death” order is in place. In all situations, the treatment team must continue the same intensive humane treatment as before, focusing on comfort.

What distinguishes PS from euthanasia or physician assisted suicide? The goal of PS is to alleviate suffering and promote comfort, not to hasten death, even though that might be a possible consequence (example of the principle of double effect). It is legal in the United States. The goal of euthanasia is to intentionally hasten death, usually with a goal of lessening or avoiding suffering. Euthanasia is not legal in the United States. Physician-assisted suicide involves providing a person with the information or means to enable the person to end his or her life, including prescribing or supplying the medications. It is legal in some states. Clarifying these distinctions will likely benefit parents, the child/adolescent, and the staff.

- What is the “double effect”? The “double effect” reasoning states that an action (such as PS) undertaken for a proportionally grave reason with potential harmful effects that are inseparable from the good effect is justifiable if the following are true:
The nature of the act is itself good (such as relief of suffering), or at least morally neutral
- The agent (healthcare provider) intends the good effect and may foresee but not intend the bad effect
- The action must not achieve the good effect by means of a bad effect
- The good effect outweighs the bad effect and the agent exercises due diligence to minimize the harm

What are the pitfalls involved in PS decisions?

- **Abuses of PS may occur:**
  - Goal is hastening death or “slow euthanasia”
  - Use when suffering is not intolerable or symptoms not refractory
  - Use of doses in excess of those required to meet goals

- **Injudicious use of PS:**
  - Potentially treatable distress missed because of inadequate assessment of child
  - Distress potentially manageable with higher doses of opioids and/or other medications
  - Failure to involve providers with expertise in pediatric pain and symptom management
  - Treating the child/adolescent primarily because of the distress of the family

- **Injudicious withholding PS**
  - Deferring use of PS while pursuing other life-prolonging treatments that do not offer adequate relief because of a desire to treat and “not give up”
  - Withholding PS because of anxiety over dealing with challenging conversations and end-of-life decisions
  - Withholding PS because of exaggerated fear of hastening death

- **Substandard clinical practice of PS:**
  - Inadequate informed consent of child/adolescent and family
  - Inadequate staff education, communication, and/or involvement
  - Inadequate monitoring of symptom distress and relief
  - Inadequate assessment of psychosocial or spiritual factors contributing to distress
  - Use of inappropriate medications
  - Inadequate family support
  - Inadequate staff support

Who is involved in the decision to initiate PS? The child, the parents, and the interdisciplinary care team are key to the shared decision making process. Parents of a minor generally provide permission based on the child’s best interest. However, assent should be sought from most adolescents who can participate in decision-making. In addition, any child with decisional capacity should be involved in the process. Advance care planning, clear goal setting for optimal palliation, and decisional support should be ongoing from the time of diagnosis. End-of-life preferences including the option of PS should be introduced if the provider would not be surprised if the child died in the next 12 months or when treatment is no longer directed to cure or prolonging life. The team should sensitively support the parents as it becomes clear that cure and prolonging life are no longer reasonable hopes. Acknowledge the parent’s distress at their child’s suffering. Support all decisions as made lovingly by good and supportive parents. “Don’t go it alone.” As this is a rare situation that is only considered after optimal pain and symptom management, providers with pediatric pain and symptom expertise should be involved. Bioethics Committee consultation is frequently beneficial. As the decisions affect the entire staff, communications should be inclusive.

On what are these decisions based?

- Our duty to optimally care for and protect the child/adolescent, including minimizing pain and suffering, balanced with minimizing harm
- Nonabandonment
• Informed consent and shared decision making including the child/adolescent according to their capacity
• Duty to ensure that we do not unduly hasten death
• Continued support of the family
• Continued support of the staff

**What one or more medications are used for PS?** The dosage and choice of the one or more medications used depends on the intensity and nature of the suffering, clinical setting, and preferred available routes. The goal is to relieve one or more symptoms according to the child’s preferences. Consultation by a pharmacist as part of the pediatric palliative care team skilled in caring for children with medical complexity is recommended.

• Benzodiazepines
  o Midazolam
  o Lorazepam
  o Diazepam
  o Clonazepam
• Barbiturates
  o Pentobarbital
  o Phenobarbital
  o Thiopental
• Ketamine
• Propofol
• Neuroleptics
  o Phenothiazines such as chlorpromazine
  o Butyrophenones such as haloperidol
  o Atypical antipsychotics

During PS treatment, encourage the family to remember the good experiences that they had with their child/adolescent. Support a legacy of memories and mementoes of their child/adolescent. Allow them time and private space to grieve.

**What should occur after death?**

• Excellent family bereavement support including meeting with the provider and/or care team
• Staff debriefing and support
• Case review and utilization review (adapted from NHPCO position statement on palliative sedation in adults)
  o Indications/symptoms
  o Pharmacologic and nonpharmacologic therapies
  o Goals of child/adolescent and family
  o Informed consent process
  o Decisions regarding other life-prolonging treatments
  o Assessment of symptoms and sedation
  o Outcomes including depth of sedation required, effectiveness for relief of suffering, and family satisfaction
  o Family and staff support
  o Complications and management
  o Process by which plan was developed

**Summary:** Aggressive symptom management by trained providers, along with advance care planning, will in many cases obviate the need for pediatric palliative sedation. In general, decisions to initiate PS should involve the child with capacity, the family, the health care team, and generally the bioethics committee to ensure an ethically sound decision and thoughtful treatment plan. If there is lack of clarity of goals or whether or not suffering is intolerable or intractable, uncertainty of prognosis, or varying degrees
of acceptance of PS, an interdisciplinary family meeting, pediatric palliative care consultation (if team not already involved), and bioethics committee consultation are appropriate. In any case, because of the complexity of symptom management and decision-making, it is advisable to seek involvement from those with specific pediatric palliative care training such as providers with certification in pediatric palliative care.

For further reading:


Cherny NI, Radbruch L; Board of the European Association for Palliative Care. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliat Med*. 2009;23(7):581-93


Clément de Cléty S, Friedel M, Verhagen AA, Lantos JD, Carter BS. Please do whatever it takes to end our daughter's suffering! *Pediatrics*. 2016 Jan;137:e20153812


Talati E. Palliation as innovation: Balancing non-abandonment and primum non nocere. Section on Bioethics, American Academy of Pediatrics. *Newsletter* Spring 2014

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Handbooks can be quick “go to” resources for providers caring for children with complex medical conditions. The fact that some of them are even available at no cost is “icing on the cake.” The handbooks described here can be very helpful for providers who have little training in pediatric palliative care and who are managing basic pain and symptoms. For children with more complicated pain and symptoms, the handbooks support and supplement but do not replace care by providers skilled in pediatric palliative care. However, management by such providers is not available in all communities. In such cases, care may be provided by adult hospice/palliative care providers. For these providers, if pain and/or symptoms become more complicated, consider consulting with pediatric palliative care providers at the regional children’s center.


**Free** copy can be ordered on-line and downloaded: [http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download](http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download)

Including the references, this is a whopping 356 pages so don’t rush out and print it all out. Needless to say, it is a very thorough document. It is from the UK, so some of the medications are different from the ones available in the US. Included in the discussion of each symptom are possible causes and pharmacologic and non-pharmacologic treatments. In addition to pain and symptom management, there are sections on neonatal palliative care, spiritual pain, emergencies in palliative care, end-of-life management, ethics and the law, psychological issues, HIV/AIDS, and travel abroad. There are 160 pages of formulary and over 20 pages of references. Didn’t I say that it was thorough?! This handbook really has a broader focus that just pain and symptom management. I liked their comments on proactive planning and preparation for emergencies and their list of indicators of deterioration/impending death. This is a handy reference to have around.

**Pediatric Pain and Symptom Management Guidelines,** Julie Hauer, MD, 2014, Dana Farber Cancer Institute/Boston Children’s Hospital, Pediatric Advanced Care Team. (Permission to freely use this manual has graciously been granted to us by Dr. Hauer.) [http://healthvermont.gov/family/cshn/palliative_care/documents/hcp_pedi_symptom_guide.pdf](http://healthvermont.gov/family/cshn/palliative_care/documents/hcp_pedi_symptom_guide.pdf)

This 27-page guide includes general information about pharmacologic management of pain, specific analgesic recommendations, and guidelines for opioid side effects. Several pages focus on pain assessment in non-verbal children. I particularly appreciated the section on the general approach to symptom management and medication use. There are guidelines for managing neurologic, GI, respiratory, and general somatic symptoms. Routes of medication delivery are explored. She makes suggestions for managing escalating symptoms at end of life. There are many well-laid-out tables. While she notes that non-pharmacologic interventions are an integral part of pain and symptom management, this resource focuses exclusively on pharmacologic treatments. Information is timely, appropriate, and concise.

Although the authors refer to their 373-page handbook as a quick reference guide for symptom management in the setting of pediatric palliative care, it is quite a bit more than that. The handbook acts as a resource to equip all practitioners, whether skilled in pediatric care or not, to provide basic pediatric palliative care. In this handbook there are included a review of pediatric palliative and hospice care, information about diseases with prognostic and trajectory information, helpful ways to enhance communication, barriers to provision of pediatric palliative care, and general pediatric and pediatric medical considerations. The section on symptom management includes causes, assessment, pharmacologic and non-pharmacologic treatment, clinical pearls, medication tables, and treatment algorithms. Several pain assessment scales are included. The information about special neonatal considerations, medication additives, measuring, palatability, look alike and sound alike drugs, lists of medications to not be chewed or crushed, and alternative forms of administration is rarely covered elsewhere. I particularly liked the sections on anticipatory guidance and the brief review of pediatric life-limiting diseases and conditions. For providers who rarely care for children, the sample pediatric intake form and information about general pediatric care will be helpful.


One reason that I find this resource helpful is that assessment guidelines, and pharmacologic as well as non-pharmacologic interventions are available in one place. In the appendix, there are multiple pain scales, adjuvant medication tables, and additional charts for things such as spirituality, steroids, family recommendations, and decision-making. It is a 155-page spiral bound book that will fit in a large pocket. Unfortunately this resource has not been updated since 2005.

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

1. **NHPCO Palliative Care Online Resources:**
   NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Also, more palliative care resources are available at [www.nhpco.org/palliativecare](http://www.nhpco.org/palliativecare), including:
   - Community–Based Palliative Care
   - Legal and Regulatory Resources
   - Webinars and Courses
   - Plus more for NHPCO members

**Palliative Care Programs and Professionals**
Join NHPCO Today!
- [Individual Palliative Care Membership](http://www.nhpco.org/palliativecare)
- [Palliative Care Group Application](http://www.nhpco.org/palliativecare) - Save by registering your entire team

2. **Pediatric Hospice and Palliative Care Resources:**
   - **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. [www.caringinfo.org](http://www.caringinfo.org)
     - *When Your Child is in Pain*
     - *Talking With Your Child About His or Her Illness*
     - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
     - *When a Child Dies: A Guide for Family and Friends*
     - *Helping Children Cope with the Loss of a Loved One*

   - **Center to Advance Palliative Care:** Did you know there are new tools to support your program? CAPC is pleased to announce the launch of three new resources for pediatric programs.
     - [Pediatric Palliative Care Survey in the CAPC National Registry](http://www.carepalliativecare.org): Submit your program data now to generate individualized performance reports on program structure and operations, as well as comparisons to other pediatric palliative care programs. CAPC membership is not required.
     - **The Pediatric Palliative Care Field Guide**: A catalog of field-wide program development tools, support sources for field research, and an updated value statement to help programs make the case for pediatric palliative care resources.
     - **The CAPC Pediatric Palliative Care Toolkit**: A collection of new, practical tools and technical assistance for pediatric palliative care programs developed by leaders and experts across the country. Available to members now in CAPC Central.

3. **Pediatric Hospice and Palliative Care Training:**
   - **9th Annual Pediatric Hospice and Palliative Care Essentials, Invitation to Submit Abstracts:** The Texas Pediatric Palliative Care Consortium and Project Joy and Hope are pleased to announce the 9th Annual Pediatric Hospice and Palliative Care Essentials Conference. The PediHOPE draws an interdisciplinary group of attendees composed primarily of professionals who provide care for children with complex medical conditions from across the nation. This includes physicians, advanced practice nurses, nurses, chaplains, social workers, hospice staff, genetic counselors, child life therapists, legislative and policy personnel, administrators, and parents. This year’s conference Creating Balance through the Journey in Pediatric Palliative Care seeks abstract themes aimed at balancing the challenges
of caring for seriously ill children and quality of life for families and health care professionals. Submit abstracts [HERE](#).

- **2017 Perinatal Bereavement and Palliative Care Conference**: For many families, expecting a baby is a time of joy and excitement. But for others, an unexpected diagnosis leaves an unending wave of sadness and guilt. Join Virtua for a day of discussion and discovery around a topic so close to many hearts in the healthcare community: perinatal bereavement and palliative care. Register [HERE](#).

- **NHPCO’s 32nd Management and Leadership Conference**
  Preconference Dates: April 29 -30, 2017
  Main Conference: May 1-3
  Washington Hilton, Washington DC
  Exhibit Fact Sheet and [Application](#)

4. **Journal / News Articles**
   - **American Children Deserve a Better Death**: Here’s one way we can give it to them. Read more [here](#).
   - **Goldstein: In Obamacare revamp, the details matter to kids**: Read more [here](#).

5. **Subjects and Contributors for Future Issues of This E-Journal.** For upcoming 2017 E-Journal issues, we plan to address issues related to: care & support of siblings and grandparents, spirituality of families and children when faced with life-limiting/life-threatening illness or death, and perinatal/prenatal hospice & palliative care. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

6. **Reader's Corner.** Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.