

Newsletter

May 2020

From the Chair

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Section on Hospice and Palliative Medicine





Remember the time when the opioid epidemic was the public health crisis most relevant to the field of hospice and palliative care?

In 2017, the U.S. Department of Health and Human Services declared a public health emergency to address the national opioid crisis. This crisis uniquely impacts the pediatric age group: from babies with neonatal opioid withdrawal syndrome, to unintentional ingestion by toddlers, on up to adolescent experimentation, misuse, and addiction. And even before the crisis declaration,

many in our field wondered how best to address symptom management and opioid access for our children receiving hospice and palliative care.

I expected to learn about opioid dosing, delivery, and rotation in my Hospice and Palliative Medicine fellowship. I was a bit surprised to realize I needed to think about diversion, whether local pharmacies kept opioids in stock (safety concerns), and how to address patients or parents who refused certain opioids because of perceived addiction risks. It's only been since the HHS opioid crisis declaration that my own hospital has implemented an opioid stewardship program – years later than when they created such a program for antibiotics. I have so much more to learn, consider, and advocate for when it comes to opioids. The content of this SOHPM newsletter is a great *antidote* to my deficits. The editors *dose out* experiences, perspectives, knowledge, and resources relevant to opioids. (*The italicized puns are totally intentional*.)

And as I write this "Letter from the Chair" I'm pondering how the fields of public health and palliative care may both look in the months and years following the COVID-19 pandemic. Will there be newfound public recognition of the role public health, vaccines, and medical training have to offer? Will more people have contemplated mortality and be inspired to complete advanced care plans and consider how much is too much? Will this experience of community grief and uncertainty connect us to our patients and families and each other in more meaningful ways? Such outcomes are what I am hoping for as I write to you.

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Methadone for Pain in Children By: Kevin Madden, MD, FAAP

Methadone has a special place in our pharmacopeia. It's a tremendously important medication, but it is shrouded in mystery and danger. Well, kind of. My initial interest in its use in children with pain started simply because I am drawn to the unusual. Everything about it – its pharmacokinetics and pharmacodynamics, its mechanism of action, its side-effect profile, its historical use in modern American medicine – distinguishes it from other mu-receptor agonists we use. Almost everyone I worked with had a different value for what constituted prolongation of the corrected QT (QTc) interval. Almost all of the consulting services were nervous about prescribing it when I recommended it. Yet methadone is the only long-acting opioid available as a liquid, which makes it an attractive medication in pediatrics in children who cannot reliably swallow tablets or depend on a gastrostomy tube. This all morphed into clinical research on various aspects of methadone.

The main clinical concern of a prolonged QTc interval is that it can lead to torsade de pointes (TdP), a potentially fatal arrhythmia. The variability on how to define the threshold value of a prolonged QTc can lead to somewhat arbitrary decision making on how to use methadone, whether to wean it or whether its use is contraindicated. As a result, we risk underutilizing an important medication from among our tools to minimize suffering in children.

Our initial question was what people consider a prolonged QTc interval to be. One of our first studies showed that pediatric palliative care physicians reported the value a prolonged QTc was (median, inter-quartile range) 450 (440, 478) ms ⁽¹⁾. This is a commonly taught value but compare this to normative pediatric QTc values (99-99.5th percentile) ^(2,3):

- 460 ms in prepubertal children
- 470 ms in adolescent males
- 480 ms in adolescent females

In general, pediatric palliative care physicians underestimated the value of a prolonged QTc. But there were many who overestimated the value as well. We found a bimodal distribution of the most commonly reported threshold values, 450 ms and 500 ms⁽¹⁾. The 500 ms value is important because at this crucial inflection point, the risk of developing TdP changes from linear to exponential. So, while 500 ms is higher than the normal values, it does represent a clinically significant value.

We next sought to determine the frequency of prolonged QTc in children and adolescents before and after starting methadone. How common was this side effect? In two retrospective studies with a total of 56 patients we found no patients had a baseline prolonged QTc and only two developed a prolonged QTc. A closer look found that one patient had a history of prolonged QTc that the family had not disclosed and the other had multiple electrolyte abnormalities ^(4,5). Neither patient developed TdP. The two prolonged QTc values resolved with discontinuation of metha-

done and correction of electrolyte abnormalities, respectively. Hypokalemia has consistently been found – more than any other electrolyte abnormality – to be associated with both increasing the QTc interval and the development of a prolonged QTc.

We next examined its effect in the treatment of nociceptive and mixed nociceptive and neuropathic pain. Does it work the way we think it does? In children started on methadone 0.1 mg/kg by mouth every 12 hours, with a maximum dose of 5 mg by mouth every 12 hours, we found reduced patient- and parent-reported outcome measures of pain, insomnia, and fatigue (6). Approximately 14% of patients needed an increase of methadone during the study period. In light of some of the anxiety physicians have to start methadone, it is important to note that only a small minority of patients (12%) needed a reduction in methadone, and all reductions were due to a resolving pain syndrome and not because of side effects. Additionally, an unpublished quality improvement project of ours followed 23 consecutive outpatients after starting them on methadone. Their families were phoned by a doctor or pharmacist on days number 1, 3, and 5 after starting methadone. We found no side effects, asking particularly about myoclonus, hallucinations, or excessive somnolence. We found methadone to be a very safe medication to start in both the inpatient and outpatient setting.

Methadone's multiple mechanisms of action are likely what makes it effective for chronic pain management when compared to primary mu opioid agonists such as morphine or oxycodone. Instead of modifying the nociceptive input of pain at one receptor, methadone acts on the mu, delta, and kappa opioid receptors as well as antagonizing the NMDA receptor and blocking reuptake of 5-HTP and norepinephrine. All of these neurotransmitters and receptors play some role in the modulation and perception of pain. This becomes especially important in our approach to neuropathic pain, which is notoriously difficult to treat given its rapid and unpredictable onset, lack of reliable inciting or exacerbating factors, and the lack of a definitive drug of choice (gabapentin, pregabalin,

duloxetine, and tricyclic antidepressants all are considered acceptable first-line treatment).

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A Seemingly Precarious Path: Symptom Management and Addiction By: Steven Smith, MD, FAAP

Quiet and somber is what I remember in my last interaction with "Michael." Little was said, but much was communicated. He was actively dying. His grip in my hand spoke to the two-year odyssey we had set out on together. The odyssey led us to this point, and on the way it revealed more about me than I could have imagined.

We first met each other during a hospital admission. He was a young adult trying to navigate the waning days of his illness. His admissions were proving less and less effective in getting him to his previous baseline, and his team consulted our palliative care team. He recognized that his body was becoming frailer, as if he were descending steps on a ladder with each admission, resulting in increasing weakness and diminishing returns. With each admission he felt less like himself.

Our initially reserved conversations began drifting deeper over time. He would light up when discussing his son, opening the door to more sacred conversations. He began sharing how difficult and vulnerable it felt discussing goals he feared he might never achieve. Eventually, though, he developed the confidence to voice his hopes and worries, often framing them around his family. He disclosed his yearning to be home, with his family, with his son. He confessed how the admissions kept him from spending time with family, stealing pieces of the precious time that remained.

As our relationship grew, Michael shared more about the toll his condition had cost him in life, including his history of opiate addiction. I had known of this history before our meeting, but the interplay of his worsening disease and his history of addiction became more apparent. He acknowledged his back and forth relationship with opiates, treasuring their symptomatic relief but hating what they had done to his life in the past. He oscillated from fear to appreciation, and confessed at times he experienced the old specter of his addiction.

Over time, the impact of his disease became more tangible. A relationship that began with mutual trust descended into more reserved and quiet conversations. His medical team and our palliative care team began having concerns around his use of opiates, and the character of our discussions with him changed. He was less willing to discuss concerns he had previously shared openly. We worked to pave a path towards safe management of symptoms in this context, but I admit that as time progressed I developed an element of skepticism, concern, and even alarm. I feared contributing to a relapse in his addiction, and this interplay began creating distance between us, a distance that I was also responsible for creating. Instead of being present in the moment with him, my mind would wander to how to safely manage his symptoms, how to prevent misuse and relapse, and to the safety of him and others. A piece of clinical data, his history of addiction, had anchored my presuppositions and bias and, I hesitate to admit, my judgement.

As pediatric palliative providers, our symptom management often intersects with the struggle of opiate misuse and addiction. As our screening and best practices evolve, so does our awareness of this dynamic. The impact can range in severity but, especially in the outpatient setting, we can expect it to have a greater influence in our practice. Unfortunately, this presents challenges and uncertainty. In this context, balancing good symptom management with good evidence-based treatment of addiction is an essential but delicate dance.

I find myself struggling with the competing themes of symptom management, addiction, and my patient's current addiction management while maintaining a strong therapeutic relationship. The pendulum may swing too far to one side or the other, either contributing to worsening addiction or being dismissive towards symptoms and inadequately treating them. All the while trying not to risk my therapeutic relationship with the patient and their family.

In our current era of risk assessment and mitigation, we can lose sight of the human element sometimes. Not to be mistaken, I think these screenings, discussions, and safety plans are crucial to providing effective and safe patient care. However, as time wore on with Michael I began to notice our visits became less effective. I was wearier. It began to cost my empathy, a piece of me that defines my practice. Initially, I fell into the trap of attributing this to his flaring opiate addiction; as I took stock, I realized my contribution to our faltering relationship. Noticing the changes in me, I began an internal interrogation of the spirit of my practice. I realized I had transitioned from meeting my patients with addiction where they were, to a posture of constant vigilance, ever mindful to ensure nothing suspicious or nefarious was afoot. I may have checked the boxes of good evidence based opiate prescribing, but its cost was much of my patient physician relationship.

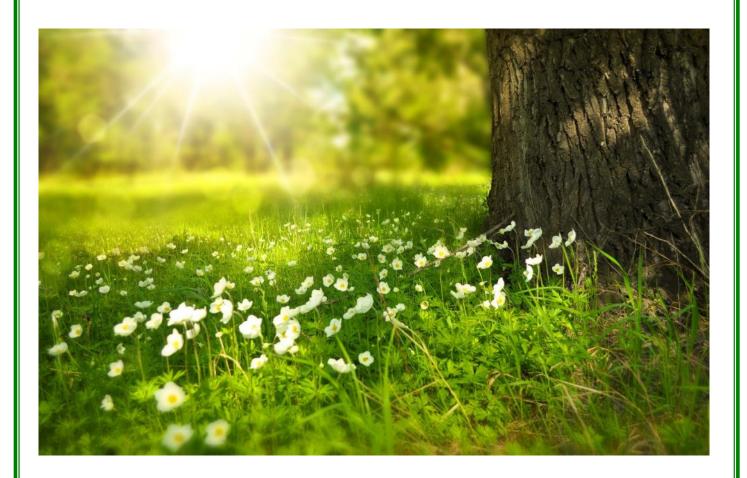
Following this revelation, I shifted. I began looking past my own bias and fears, instead focusing on being present in the moment. This served as a doorway to more proactive and strategic palliative care. In Michael's case, I learned to see his struggles with addiction as another part of his narrative that demanded empathy. At the same time, he demonstrated a new willingness to engage in conversations and effective management of his addiction. Our changes resulted in synergy. Instead of working around his addiction, we were able acknowledge it and, in a spirit of transparency, discuss its effects. I became empowered as a clinician to provide additional compassion, approaching these discussions holistically. This balance of medical, psychosocial, spiritual and psychologic needs, empowered Michael to honor his story. Likewise, it also empowered me to do what we do best in palliative care – see the patient as a whole and as a partner in his medical care. Together we built a more collaborative plan.

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Many members of our interdisciplinary palliative team made a fundamental difference in his care. In addition, Michael's renewed transparency about his addiction concerns and our improved partnership led to adding an addiction specialist to his interdisciplinary team. We did better at balancing symptoms with judicious use of pain medications in a safe and effective way. Not only did this help us ensure we were being mindful throughout his disease course, it provided Michael with the peace of mind to know we had an expert in addiction involved.

In the hospital, surrounded by loved ones and family, Michael looked back at me with confidence and trust. To pretend the jour-

ney did not have its challenges or times of uncertainty would cheapen the narrative. We both stretched each other in ways that inspired growth. In this moment I was able to look back and, as the ending of our story unfolded, realize the lessons. I remember once hearing that the courageous part of palliative care is running into the room when everyone else is hesitant (or running out). We run in to tackle the difficult subjects and opiate addiction is no different. We have to see the challenges, acknowledge the hard truths, then look at the whole person and ask, "How can we help you live your life to its fullest?"



"C" Your Inner Author By: Meaghann Weaver, MD, FAAP

With so many pulls and pressures in our field, the idea of writing a paper may sound like an unrealistic task best reserved for "the researchers". Our field is a field of narratives and words. People passionate about the field of palliative care are all keepers of words, whether or not the narratives have been formally acknowledged on paper by the author. Let's encourage one another to foster the idea of palliative care team members as listeners of life messages which are worthy of writing.

Write with Conviction, Creativity, and Compassion – Write the convicting messages that life has share with you. Write to share about the memories that you ponder on the drive home from the hospital. Write to creatively process a meaningful palliative care moment. Write with the compassionate recognition that a story has been gifted to you through certain encounters or experiences and that story is worth exploring and sharing.

Write without Self-Criticism – Remember that you are the author not the editor in your first draft. Your first draft will be tangential. Your first draft may have words that you made up or sentences that you fragment. Write an uninhibited initial paper and refine it later. Your first draft has permission to be one long run-on sentence that would make any Literature Professor blush. Your first draft is for you. Your final draft may not be reminiscent of your first draft because writing is an iterative, engaged, ongoing process.

Write with Clarity – Draft an outline of your paper paragraphs and letting that guide your writing. Keep your main message close-by as you write. Consider writing the objective or paper purpose in the header line of your typed document. Seeing the main point on each page can remain as a visual reminder to remain within the context of your outline.

Write with the Confidence of Curiosity – Give yourself permission to write because you are curious about a topic not because you are an expert on the topic. Background research and reading preparation can serve as the mechanism for learning about the topic. Confidence can come from curiosity rather than expertise. I write because I wonder – not because I've arrived at full knowledge.

Write using a Curriculum – Consider enrolling in a course through a nursing, public health, or communications curriculum. Auditing the course may lift performance pressure. The structure of a syllabus and access to research methods can be helpful.

Write with your own Circadian Rhythm, a Clock and a Calendar – The day of a pediatric palliative care team member rarely offers the luxury of "free time" to write. Leverage your most productive hours and recognize those may be unconventional times such as early morning before sunrise or when your space is quiet but your mind is loud. If your best writing time is during the work day, try blocking that time on your calendar as a commitment to write.

Write with awareness of the Critics – The favorite paper that I ever wrote (a narrative about how immigration policies impact access to palliative care) remains unpublished. The Reviews were harsh and I couldn't bring myself to temper-down the message. Recognize some papers won't be received with the same enthusiasm with which you write them. Keep writing.

Write in Community and with Collaboration – Write and process together with others. Write with colleagues from other disciplines for the diversity of shared understanding. Reach out to collaborate and partner. Join or create a community of pondering thinkers or do-ers and write what you are together pondering. Invite others to join your research and writing teams.

Write for your Colleagues – If you learned from a complex or challenging case, publish a case report. If you improved a health system or leveraged a quality improvement project to enhance palliative care, write to share the approach with other centers. If you invested time researching symptom management or a complicated disease process, share what you discovered in the form of a scoping review or narrative summary. Think of the time you invested in the process and the time you could save your colleagues who encounter the same clinical question later. Gift your colleagues with shared learning.

If you self-identified as a clinician or care team member in 2019, I urge you to consider expanding your identity to also include clinician-writer in 2020. The field of pediatric palliative care is advanced through shared research and writing. Tap into your inner author!

Books Relevant to Pediatric Palliative Care

This is a list of books relevant to the field of pediatric palliative care shared through the American Academy of Pediatrics (AAP) Section on Hospice and Palliative Medicine (SOHPM) PPCAAP LISTSERV®. The perspectives and content within these publications are not endorsed by the SOHPM or the AAP, and do not necessarily reflect the perspective of the SOHPM or the AAP. This list is being shared for informational purposes only. This list is not exhaustive and other mentions and or books may exist.

An author and/or editor name in bold indicates they are a SOPHM member.

Title	Authors and/or Editors	Publication Year
The Gifts of Gerbert's Feathers	By Meaghann Weaver , Lori Wiener and illustrated by Mikki Butterley	2020
Perinatal Palliative Care: A Clinical Guide	Editors: Erin Denney-Koelsch and Denise Cote-Arsenault	2020
Pediatric Palliative Care: What Do I do Now	Edited by Lindsay B Ragsdale and Elissa G. Miller	2020
A Field Manual for Palliative Care in Humanitarian Crises	Edited by Elisha Waldman and Marcia Glass	2019
Handbook of Perinatal and Neo- natal Palliative Care A Guide for Nurses, Physicians, and Other Health Professionals	By Rana Limbo, Charlotte Wool, and Brian S. Carter	2019
Follow the Child Planning and Having the Best End -of-Life Care for Your Child	By Sacha Langton-Gilks	2018
Las Chicas Son de Ciencias 25 Cientificas Que Cambiaron El Mundo	By Irene Civico, Sergio Parra and illustrated by Nuria Aparicio	2018
Bearing the Unbearable Love, Loss, and the Heartbreaking Path of Grief	By Joanne Cacciatore Foreword by Jeffrey B. Rubin	2017
Sun Kisses and Moon Hugs	By Susan Schaefer Bernardo and illustrated by Courtenay Fletch	2017
A Really Practical Handbook of Children's Palliative Care for Doc- tors and Nurses Anywhere in the World	By Justin Amery	2016

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Title	Authors and/or Editors	Publication Year
Voicing My Choices	Pediatric Oncology Branch, National Cancer Institute and the National Institutes of Mental Health at the National Institutes of Health	2014
Textbook on Interdisciplinary Pediatric Palliative Care	By Joanne Wolfe, Pamela S. Hinds, and Barbara M. Sourkes	2011
Pediatric Palliative Care Consultant Guidelines for Effective Management of Symptoms	By Melissa O'Neill Hunt, Bridget McCrate Protus, Janine Penfield Winters, Diane C. Parker	2008
Elsewhere	By Gabrielle Zevin	2005
Raising an Emotionally Healthy Child When a Parent is Sick	By Paula K. Rauch and Anna C. Muriel	2005
Understanding Your Grief Ten Essential Touchstones for Finding Hope and Healing your Heart	By Alan D. Wolfelt	2004
I Wasn't Ready to Say Goodbye Surviving, Coping and Healing After the Sudden Death of a Loved One	By Brook Noel and Pamela D. Blair	2000
The Next Place	By Warren Hanson	1997
Armfuls of Time The Psychological Experience of the Child with a Life- Threatening Illness	By Barbara M. Sourkes	1995
The Fall of Freddie the Leaf: A Story of Life for All Ages	By Leo Buscaglia	1982
Stages of Faith The Psychology of Human Development and the Quest For Meaning	By James W. Fowler	1979

Opioids and End of Life Care: A Nurse's Perspective By: Michelle Weisz , RN

Even with 19 years of experience as a pediatric bedside nurse, I have cared for only a few patients at the end of life, because there are not many children who die on our unit. The handful of experiences I personally have had were thankfully a peaceful and comforting time for the family and staff. While we have many ways to enhance comfort, opioids have been a helpful tool that can help to ease a patient's pain and suffering, while also providing an opportunity for the child to interact with his or her surroundings.

The experiences that I have had caring for patients at the end of life have been with families in the hospital who have the support of our pediatric palliative care team, and often the local hospice agency has been involved as well. Through my involvement with these brave and loving families, I have learned about the transition from life to death and the common fear that parents have that their child will suffer from pain or breathlessness. I work with these parents to protect their child from as much discomfort as possible. I want to tell you some of their stories.

A 17-year-old young man with cancer. His family surrounded his bedside until his final breath. His mother shared with me that her biggest fear was that he was going to die in pain. We managed his pain with IV and then sublingual morphine. He would have moments of alertness in between hours of peaceful sleep. When he was awake, he sometimes envisioned himself away from the hospital, but he always recognized his family. One day I was caring for him when the room was full of visitors. With his eyes closed, he asked for a moment with just his mother. The mom asked me to stay with them, which I did for extra support. "I want to call Aunt...on the cell phone." His aunt, who was a minister, asked him if he was afraid to die. He said, "No, I just want you to sing The Old Rugged Cross." Surprised by his request, she hesitated, but then proceeded to sing the most beautiful rendition of his beloved hymn. His mother and I held hands, crying as we stood in the dark near his bedside. It was so peaceful to the patient. It was so lovely for the mom. I knew that the comfort medications had allowed the state of relaxation that

created such a healing moment between his aunt, his mother and him. When his aunt was finished with the song, he said, "Sing it again please." He died that evening.

An 18-year-old young man at home on hospice. As his pain was becoming challenging to control at home, his mom agreed with hospital admission for symptom management. Knowing how little he complained and his high pain threshold at baseline, his mother advocated for pain management. Hearing his mom's concerns, the team started him on scheduled opioids. They discussed with her the physical signs that can be monitored to optimize management of his pain. Knowing that his symptoms were now well controlled allowed her to just be present with him, lying next to him and sharing memories at the bedside with family. He died two days later. His mother shared with staff how much she missed him already, but she took great comfort knowing that he died peacefully and without pain.

A 5-year-old who lived longer than his doctors predicted. Patients may live longer than we anticipate, which can be difficult if there is concern that the child is suffering, but a gift of time if the patient is comfortable. Knowing that we were managing his symptoms, this family was able to focus on quality time to create meaning. They spent time making handprint memories, having a professional photographer come, and having the time to say goodbye. He died 5 days later on our unit.

As a nurse, I would be frightened to support patients at end of life without an array of tools to address symptoms, especially pain. In particular, I have seen the comfort opioids can provide to patients at the natural end of their life. Partnering with the three families above reminds me how meaningful our work is at such a difficult time. We help families to create a lasting memory of their loved one at peace and creating an opportunity to say goodbye. I am truly honored to be part of that healing and peaceful time, and I am grateful for the many tools – opioids and other comfort medications, relaxation methods and music – to support these brave and loving families.



Parent Column Breathe By: Brenda Murray

I will never forget the doctor's words: "I'm prescribing him morphine." In my mind I can still see my husband and myself sitting next to Sam in his wheelchair in that small clinic room. The doctor had spent 20 minutes examining Sam, even watching him have an episode.

Sam no longer needed to be asleep to stop breathing; it was now happening when he was awake. With changing anatomy and increased muscle tone, his tongue could occlude his airway at any time, and the smallest amount of swelling from a simple cold made it much worse. Unable to ambulate and with no head control, he could no longer keep his own airway open. He knew it, too. Nothing scared us more than the panic in his eyes during an obstructive episode. To this day, I have never encountered a look of terror like that.

Each night, positioning him for sleep, we played a ridiculous game of pillow Jenga. Carefully and methodically, we would prop his chin with a series of cushions and pillows, maintaining gentle upward pressure to keep his airway open. It was a volatile situation, to say the least: one wrong move and the tower would crumble. More often than not, despite our efforts, the pillows would shift, and we would be awakened by his gasps for air. From deep sleep we were suddenly running at full speed to Sam's bedside, often to find him already turning blue. A quick chin thrust and Sam would take a big breath. How long had he been apneic? We never knew.

"Morphine? Are you sure?" I couldn't wrap my mind around the doctor's words. I had memories, as a teenager, of my great uncle living with us as he neared the end of his life. I vividly remember the hospice nurse handing the bottle of morphine to my parents with instructions on when and how to use it, explaining to us how the end might look. I had never heard anyone talk so candidly about death, and it was demystifying. I wasn't afraid anymore. We were at peace, with a plan to ease his discomfort if he struggled to breathe. There would be no panic.

Now, hearing that my son needed morphine, it meant the beginning of the end. Or at least I thought it did. I was apprehensive. There was a definite stigma attached to it. What would I tell Sam's home nurses? Would they refuse to use it? Would they judge us for giving it to him?

I voiced my concerns to the doctor. It wasn't until he explained in simple terms what we were doing that we understood how morphine aligned perfectly with our wishes for "comfort over cure". When an airway occludes, the primal instinct is to take a deeper breath. When the airway is blocked and prevents this, the gasping - and the panicking - begin. Air hunger.

Sam's doctor taught us about air hunger, explaining that morphine attaches to certain receptors in the brain, calming that primal reflex to gasp for air. Eliminating the panic. The doctor assured us that used appropriately, morphine would not stop Sam from breathing or hasten his death. Yet again, I was reminded how education takes away fear.

In an effort to ease my maternal guilt, and to reassure Sam's nurses that adding an opioid to our already-full drawer of medications was a necessary next step, the doctor wrote in Sam's chart:

"He can have a lot of distress with this. There is not, unfortunately, any simple remedy. If you were considering procedures that would prolong life, a trach may help but I agree that this is really not in his best interest and would be prolonging suffering. I am going to provide some morphine to use if you feel he is in distress from breathing issues. This will NOT accelerate a dying process if one is occurring, it is simply a humane way to give him comfort."

We left clinic with the prescription and an overwhelming peace, knowing we now had a "tool" to use at home to bring Sam comfort in times of distress. I realized I had been asking Sam's doctors for exactly this for the past 14 years. It wasn't until now, when his symptoms had become so extreme, that I was finally given something I felt could truly help him.

Although a bit apprehensive, Sam's nurses agreed this was an appropriate next step. As it turned out, more often than not, he needed morphine when they were not on duty, leaving us to make educated decisions on when it was necessary. Initially we were a bit nervous, but we eventually realized that no one else knew Sam better than we did. We were the experts he needed.

Over the next year, morphine was exactly what Sam needed. His episodes were happening more frequently. Unfortunately, it was not long before a new problem developed. Even tiny doses under the tongue became unbearable. He would choke and gasp, and as I suctioned his mouth I knew full well I likely suctioned out the morphine. We were advised to administer morphine via his gastrostomy tube. It was less effective and slower, but it was the best we could do.

As Sam's body continued to change, his symptoms became more severe, and his condition deteriorated rapidly. Severe neurostorming episodes seemed to come from nowhere, and were excruciatingly painful. His body would stiffen, straight as a board. Sweat quickly soaked his sheets, and he would scream in pain. Morphine via gastrostomy took too long to work. We needed something faster.

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Palliative care offered another medication: intranasal midazolam, intended to stop neuro-storming episodes quickly. Although not an opioid, obtaining approval for it proved to be extraordinarily difficult, generating copious email correspondence with physicians, pharmacists, social workers, and state employees. Requests for midazolam for pediatric Medicaid patients were uncommon: no one knew which form to fill out, which box to check, which desk to darken. The paperwork and red tape were maddening, for all of us.

One day, 6 months and 85 emails later, my phone rang. It was a gentleman from the state, asking if I was awaiting approval for midazolam for my son. The paperwork was sitting in front of him, and he would put the approval through that day. It had finally made it to the right desk! To this day, I do not understand why this took so long, or happened this way.

Midazolam worked exactly as we had hoped. Sam's body would respond within seconds, the episode would dissipate, and his pain and agony would ease.

Due to our great difficulty obtaining midazolam, the palliative care team wanted to ensure we had another option available, and we were offered intranasal fentanyl. Much to our surprise, this was approved almost immediately! There seemed to be no rhyme or reason to medication approvals. Once again, though, there was a hitch. Soon after filling the fentanyl prescription, I heard from Sam's palliative care nurse practitioner, who had received a call from the "Transmucosal Immediate Release Fentanyl (TIRF) Risk Evaluation and Mitigation Strategy Program (REMS)". She had been told Sam's fentanyl could not be refilled: it could be used only for intractable cancer pain, and Sam did not have cancer. We had one sacred dose.

Over the next year, my gut told me we were speeding towards a brick wall. We continued to focus, more than ever before, on

comfort for Sam, with the aid of medications and common-sense interventions. Seemingly simple things: comfortable pillows, soft music, good hygiene, and above all else unconditional love.

Due to a billing issue, we were not allowed the privilege of having hospice care for Sam. We were forced to choose between keeping our home nurses, a part of our lives for 12 years, or transitioning Sam to formal hospice care. We chose to keep our home nurses, knowing full well what this meant. We were now Sam's hospice providers.

Our connection with pediatric palliative care was now more important than ever, and with their help we were able to provide Sam the end of life he deserved. After a short but severe respiratory illness, Sam peacefully took his last breath. He was resting comfortably in his own bed, with me and my husband at his side. In the end, his body knew exactly what to do, and with a little help from us, did just that. Our job was not to fix but to support, watching carefully as his body gave us cues as to what it needed. In his final week, only the lowest dose of morphine was needed, and that only a handful of times, to ease his discomfort.

We fought hard to ensure Sam experienced humane comfort, particularly at the end of his life. I would do it all again for the peace we retain, knowing he did not suffer.

~ Brenda lives in Stevens Point, Wisconsin. She is wife to Joshua and mother to 3 sons: Samuel, Simon and Solomon. Samuel sustained a massive bilateral stroke in utero, leaving him with cerebral palsy, cortical blindness, intractable seizures, and many other diagnoses. He was medically fragile since birth, non-verbal and non-ambulatory, and needed complete and total care

every day of his life. He passed away on September 27th, 2018 at the age of 15.



Fellow's Column By: Priyal Patel, DO

Anxiety? Check! Diaphoresis? Check! Palpitations, lightheadedness? Check, and check! Wait: is this the patient, or is this me? An internal review of my own systems found me increasingly questioning my own sanity. Distressed and desperate, I clenched my teeth as I entered yet another order to escalate a patient's opioid. I tried to soothe myself with internally whispered reassurance: highly intelligent physicians and pharmacists had instructed me at the start of my hospice and palliative medicine fellowship that it is OK, even laudable, to escalate opioid as needed to achieve acceptable symptom management. If a patient is tolerating a given dose without achieving desired efficacy, up-titrate as needed, particularly during end-of-life management when symptom burden often escalates rapidly. Actually ordering what felt like elephantine doses of opioid, however, was making me uneasy.

Before this, I had never questioned my comfort level in escalating opioid. By this point in my career I had already completed a residency in pediatrics and a fellowship in hematology-oncologybone marrow transplant, in the course of which I had seen colleagues in palliative medicine rapidly and effectively escalate medication dosing during end-of-life care for numerous patients. In the final 2 hours of her life, for example, a patient with metastatic alveolar rhabdomyosarcoma had rapidly progressive dyspnea and agitation requiring 3 dose escalations of her morphine and 2 dose escalations of her lorazepam, each providing progressively better symptom relief and ultimately a peaceful death. I was able to visualize, and thus to understand, the benefits of dose escalation in this patient, and never once questioned doing so. The difference between that case and my current patient seemed obvious. Previously, I was not the physician making the recommendation to increase dosing. I did not "own" the regimen I was manipulating, but trusted the judgment of the expert behind the plan. Now, however, I was the palliative medicine provider in charge of managing my dying patient's pain. I was the one deciding whether rapid opioid escalation appropriate. I was even the one physically entering and signing the orders to do so. I was the expert!

I never doubted my patient needed better symptom control, especially for pain and dyspnea. I knew he needed yet another opioid escalation. I understood this was the right next step. A part of me, however, still feared that increasing his opioid might impair his breathing or even hasten his death. Particularly for a palliative provider, such fears may seem illogical, but in that moment they were profoundly real. His villainous cancer was invading his lungs, eroding his bones, leeching blood and nutrients away from what little healthy tissue remained in his body. A once robust appearing young man, he was now eerily thin, seemingly made up mostly of cancer. His face told of pain, fatigue, and despera-

tion. His parents and little sister stood nearby, glaring helplessly at me. All of them were counting on me to provide the comfort he desperately needed. The family was terrified by his discomfort; I was mortified by mine. His father asked, "Will he live much longer?" I tried to prepare them as best as I could for the inevitable, that he likely had hours-to-days at best. His urine output had dropped off, his skin was ashen and dusky, his extremities were cold, and he was in an out of sleep: he would likely die soon. His mother worried, "Is he suffering? Can he feel the pain?" I counseled her on the signs and symptoms of end-of-life. He may have dyspnea, confusion, apnea, pain. There may be a rattling sound in his throat when he breathes. I told them we would monitor him closely for discomfort, promised I would make him as comfortable as possible, and assured them I had the tools needed to help him. At that moment, I took a deep breath and reaffirmed to myself that opioids were one of those tools.

Thankfully, I had been taught well by multiple skilled and compassionate mentors and educators, and this helped ease my anxiety over escalating opioid to optimize symptom control. That realization, reinforced by the support I received from the interdisciplinary team around me, allowed me to do what was needed to manage my patient's symptoms effectively. He needed more opioid, and escalating doses provided him with much needed comfort. The wrinkles in his forehead smoothed, the tension in his face loosened, the furrow in his brows relaxed. His dyspnea improved, and he looked more at ease.

This experience occurred at the very start of my fellowship in hospice and palliative medicine. I have since encountered similar situations many times. Although the anxiety behind each judgment call has decreased, the lesson of the important though process underlying each judgment call has not been lost. My education, and the resources I have available, have prepared me to manage patients who need escalating doses of opioid. The butterflies in my stomach over opioid dose escalation still flutter, albeit somewhat less than before. Anxiety? Check! And that's OK.



Resources

From the American Academy of Pediatrics: Resources Related to Opioid Use

American Academy of Pediatrics (AAP) Committees and Sections that work on opioid related issues include the following:

- Section on Hospice and Palliative Medicine
- Committee on Drugs
- Committee on Substance Use and Prevention
- Section on Anesthesiology and Pain Medicine
- Section on Integrative Medicine

AAP Policy on topics relevant to opioid use include the following:

- Pain Assessment and Treatment in Children With Significant Impairment of the Central Nervous System.
- Policy Statement: Substance Use Screening, Brief Intervention, and Referral to Treatment
- Clinical Report: Substance Use Screening, Brief Intervention, and Referral to Treatment
- Medication-Assisted Treatment of Adolescents with Opioid Use Disorders
- A Public Health Response to Opioid Use in PregnancyRecognition and Management of latrogenically Induced Opioid Dependence and Withdrawal in Children
- Codeine: Time to Say "No"
- Prevention and Management of Procedural Pain in the Neonate: An Update
- Relief of Pain and Anxiety in Pediatric Patients in Emergency Medical Systems

AAP Educational Materials:

PediaLink Module — Chronic Pain and the Opioid Crisis

This course reviews the types of chronic pain pediatricians are likely to see in their patients. The role of opioids in the treatment of chronic pain and Centers for Disease Control and Prevention (CDC) recommendations are discussed. This course is free.

AAP Pediatrics for the 21st Century (Peds 21) – Video Recordings

This symposium, Opioids Through the Ages: Caring for Children and Families in the Wake of the Opioid Crisis, from the 2019 AAP National Conference & Exhibition examines the impact of opioids on child health from the prenatal period through adolescence, providing pediatricians with knowledge, tools, and resources to help patients and their families.

Additional information about AAP Opioid Initiatives can be found here.

Resources

From the American Academy of Pediatrics: Resources Related to COVID-19

As the COVID-19 pandemic evolves, the AAP has been staying abreast of all confirmed developments related to its global spread and will continue to be vigilant in efforts to develop and share information and guidance with members and the public.

source, AAP Guidance: Telehealth Payer Policy in Response to COVID-19, which outlines policy changes aiming to alleviate barriers to telehealth care. In addition, see how your state is responding to this crisis in these State Notices on Telehealth Policy.

Clinical Guidance and Education

The AAP recommends following the latest guidance from the CDC on infection prevention and control, including the use of Personal Protective Equipment (PPE), as well as in making decisions about diagnostic testing. Additional clinical guidance and educational information of interest to SOHPM members includes:

Caring for Children with Medical Complexity during COVID-19 Addressing Family Mental Health Needs During the COVID-19 Pandemic

Guidance on Newborn Screening during COVID-19
Pediatric Practice Management Tips During the COVID-19 Pandemic

HealthyChildren.org Articles for Families and Caregivers

COVID-19: Information for Families of Children and Youth with Special Health Care Needs 2019 Novel Coronavirus Cloth Face Coverings for Children During COVID-19

Telehealth

The AAP offers a <u>variety of resources</u> to help you integrate telehealth in your practice, including information on <u>how to code</u> for telehealth visits. For tips on how to launch telehealth into your practice, <u>watch this webinar</u>.

The Academy continues to advocate for immediate changes to Medicaid, CHIP, and private insurers so that pediatricians can provide and be paid for telehealth care services. To support these policy changes, the AAP has developed a new re-

Advocacy

Find the latest resources and information to guide your advocacy efforts at the state and federal level during the COVID pandemic. AAP ID and password are required to access AAP advocacy resources.

Physician Wellness

Your AAP family is here for you and is offering information on self-care in this 20-minute webinar on Resilience in Stressful Times and Connecting During Times of Trauma.

Other

Webinars on COVID-19
An email designed for COVID-19 Questions
COVID-19 Discussion Board
Healthychildren.org COVID-19 Page

Provide Palliative Care Expertise and Support Physician Wellness During the COVID-19 Pandemic

Are you interested in connecting or supporting physician wellness during the COVID-19 pandemic? The AAP has created a separate chat room on the COVID-19 discussion board dedicated to supporting pediatric clinicians during this chaotic time. We encourage pediatric palliative care specialists to join this community to post your stories, challenges, strategies, and resources on this chat room to connect and support your colleagues. We would love to hear from you and support members who are feeling overwhelmed, isolated, or frustrated. AAP ID and password are required to access the AAP COVID-19.

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