American Academy of Pediatrics

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Section on Bioethics



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From the Editor Kelly A. Curran, MD, MA, FAAP



Kelly Curran, MD, MA, FAAP

Happy Holidays! This time of year is often bustling, and our household is no exception. In our family, we celebrate Christmas during

this season. Each year, I look forward to baking cookies, putting up the Christmas tree, and hanging holiday decorations with my Buddy the Elf-esque children, while attempting to rein in my husband from going full Griswold on our house. For us, the holiday season is rich with tradition.

This year, these traditions have changed slightly; it is the first year in our new house. We have spent the last several weekends bringing dusty boxes down from the attic. These boxes are full of decorations and nostalgia. While unpacking, we reminisced of the holidays at our old home and laughed about particularly ugly decorations "gifted" to us by family.

While unpacking sparked joyful memories, its results (piles of stuff) have created much consternation. The age-old dilemmas shared by the recently moved: How exactly did we get so much stuff? Where are we going to put it?

While we have found new places for many of our decorations, there are some which no longer fit. This has spurred several conversations around which parts of the holiday we hold dear and those parts we have held on to out of ritual. We have begun to edit and adapt not just our decorations, but also our customs.

The articles in the newsletter leave me with this same sentiment—reflecting on our values and past while still adapting towards the future. A huge thank you to our incredible authors, who gifted us with their insightful articles. I'd especially like to highlight our bright stars—the amazing trainee winners of the 2023 AAP/APA Ethics Essay Contest. I must recognize the efforts of Dr Steve Leuthner, Dr Becky Benson, and Ms Sue Wizniak—who are truly the gifts that keep giving. And to all our readers, no matter what or how you celebrate, wishing you Season's Greetings!



From the Chairperson: Highlighting Section and Committee on Bioethics Work Steven R. Leuthner, MD, MA, FAAP



Steven R. Leuthner, MD. MA. FAAP

With this newsletter column, I would like to highlight some of the successes of the Section (SOB) and Committee on Bioethics (COB) by sharing what the groups have been working on—from policy to the National Conference and Exhibition.

The Committee on Bioethics has recently published a statement on Responding to Parental Requests for Nondisclosure to Patients of Diagnostic and Prognostic Information in the Setting of Serious Disease. They continue to work on other statements that will be coming to fruition in the near future. A list of current policies by the COB can be found here.

While it seems biomedical ethics have typically been case-based about difficult life or death decisions in the ICUs, or about rare conditions that challenge our practices, I am encouraged the Section and the Academy are recognizing the bigger societal and cultural issues regarding ethics. A great example of this has been the Sections/Councils that have reached out to partner with the SOB for the National Conference and Exhibition (NCE) over the past several years. Working with the Council on Foster Care, Adoption, and Kinship Care, we addressed ethical issues in the foster care system, which involves more than 10 times the number of children nationally than some of the more commonly discussed ethical issues (eg limits of viability, trisomy). We have worked with the Section on Obesity to address ethical challenges in caring for youth with obesity. This was followed by a session with International Health, discussing the ethical issues in global medicine.

This past NCE, the SOB held an educational program with the Section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness and the Section on Minority Health, Equity, and Inclusion, to discuss advocating for patients at risk for healthcare inequities. While some may not consider this a life-or-death issue, these issues create great burden to the children, families,

and practitioners involved. There is national discussion on this issue as states are debating and creating laws that might protect or prohibit medical interventions for these children. This, of course, leads to internal conflict for our pediatricians caring for these children.

The SOB also submits general sessions for the NCE educational program. This year there were sessions on "Ethical Considerations in Whole Genome Sequencing for Newborns" with Lainie Ross and Kyle Brothers serving as faculty; "At a Loss for Words: Decolonizing the Language of Global Health and Health Equity," Heather Haq and Sanemba Aya Fanny serving as faculty; and Section Showcase: "Applying Ethics Principles and Tools to Advocate for Vulnerable Populations," with Vanessa Madrigal serving as faculty. There was also a plenary session on, "How Changing Legal Landscape of Abortion Impacts Pediatric Health and Pediatricians" which highlighted the effects of the Dobbs decision on pediatricians. Here again, we have a hotly debated cultural issue with laws that lead to practice conflicts.

As chairperson, I have received inquiries from members looking for help in this situation as everyone from hospital attorneys to policymakers to physicians practicing are struggling with how to approach these threatening situations. I am fully supportive of our membership reaching out to us as a resource and to share their experience and we can work together in awareness about what is happening. If you haven't already, I encourage you to get involved with your state chapters to learn more about your state laws and help advocate on behalf of the children in your state.



In this issue, we will highlight the 2023 Bioethics Essay Contest Winners:

- 1st Place: Narrative Ethics in Pediatrics by Tyler Clay, MD, Internal Medicine and Pediatrics, Medstar Georgetown University Hospital
- 2nd Place: The Destination of "Nowhere" by Daniel H. Kim, MD, FAAP, Pediatric Critical Care Medicine/Bioethics, University of Washington
- Honorable Mention: This Item Is Not Reimbursable by Joseph deBettencourt, MD, Pediatrics, Ann & Robert H. Lurie Children's Hospital of Chicago

The American Academy of Pediatrics (AAP), Section on Bioethics and the Academic Pediatric Association (APA), Ethics Special Interest Group sponsored an annual essay contest for all residents in pediatrics or medicine-pediatrics and all pediatric subspecialty fellows in North America. A review panel comprised of members from both the AAP and APA conducted a blinded review of all essays. Below are the essays that received 1st place and 2nd place, as well as honorable mention.

2023 BIOETHICS ESSAY CONTEST

1st Place Winner

Narrative Ethics in Pediatrics Tyler Clay, MD

Literature on the utility of narrative medicine abounds in adult medical literature. Rita Charon deftly defined narrative medicine in clinical practice through her concept of "narrative reciprocity," which describes the process of the clinician receiving, embodying and reflecting back a patient's story of their illness as a means of sharing power within a clinical relationship¹. In contrast to adult medicine, writing on the potential role of narrative in pediatrics is scarce, despite the powerful role of story in the rearing and education of a child. The application of narrative approaches to ethics in adult medicine, commonly termed narrative ethics, are also welldescribed²⁻⁵. Children are friends of narrative as they are introduced to the ideas of plot, character and setting early in life. In the world of childhood, narratives are utilized to sooth as much as to impart moral lessons. This piece will describe how a narrative approach is particularly well

suited for approaching ethics in pediatrics. A narrative approach can parse a child's developing autonomous self from that of their parents, contextualize information in a developing mind, stimulate a child's imagination and help foster resiliency in their care.

Narrative's Potential Role in Navigating Informed Consent: To Whom Does This Story Belong?

A narrative approach to ethics in pediatrics has the unique ability to parse out a child's autonomous self from that of the parent. Many pediatric ethical tensions center around the child-parental unit dynamic, and predominantly attempt to parse out the degree to which a child's "self" is separable from that of the parents (and the degree to which clinicians should respect that self separately). The tension between the will of the parent and that of the

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child greatly limits a principalist approach to pediatrics as it questions the role of the pillar of respect for self (aka autonomy). The concept of assent is typically utilized to help navigate these tensions and the American Academy of Pediatrics' Committee on Bioethics (AAP COB) has drafted recommendations on navigating informed consent in pediatrics.

Narrative medicine is well-poised to tackle the parsing of a child's story from that of a parent/guardian. Pediatric histories portray a type of "nested story", as Rita Charon describes them⁶. Nested stories occur widely throughout the written word. Oftentimes such a framing device for a story begs the reader to question the trustworthiness of the narrator. The history of a child's disease (and often their life) is recounted to the pediatrician oftentimes mostly from the parent. While this second-hand recounting of a disease-process should not engender distrust in the narrator (the parent), it should act as a call on the provider to seek out a "first-person" perspective. The purpose of narratively distinguishing the child's "story" from that of the caretaker is not to discount the caretaker's narrative, but to underscore the role of the child in their care in an effort to complement the child's sense of agency.

Narrative's Potential Role in Contextualizing Care: Narrative Emplotment

The AAP COB's recommendations state the importance of contextualizing the clinical situation at a level appropriate to the child's stage of development. Though many models for cognitive development by age exist (for example Piaget), children can develop differing levels of maturity of thought at a variety of ages depending on other factors, including underlying developmental disorders and chronic conditions. This variability in development and cognition can make ascertainment of the child's understanding of their illness or clinical situation difficult. A narrative approach is an appropriate strategy to determine a child's understanding of their situation and further contextualize their illness.

Narrative emplotment can be used to help ascertain and contextualize a care trajectory for pediatric patients. Rita Charon uses the term "narrative emplotment" to describe the general mechanism of a narrative means of contextualizing a disease process⁶. In a narrative bioethical approach, emplotment would be achieved primarily through the use of questions aimed at framing the situation narratively. Questions could be framed to elicit and understand the patient's story while also helping a cognitively developing mind further understand their own condition. The approach might employ creation of a timeline, highlighting action and consequence and eliciting the role of other persons (characters) in the illness story. Questions would elicit understanding and experiences, important relationships sustained or lost, sources of support and encouragement, etc.

Importantly, this conceptualization of narrative emplotment is distinguishable from that of Charon's in adult medicine in that the "illness story" elicited from a child would here be formed in partnership with the child, whereas Charon broadly advocates for a patient's story to stand on its own, with the provider acting mostly as a receiver and then reflector of that story back onto the patient. As children may require more guidance and probing to elicit details and provide structure to the story, forming the story in partnership with the provider would be necessary.

By eliciting a patient story with narrative intent in mind, a child's story will bloom to its highest potential to inform their care and it will also effectively contextualize the illness for the child and others. Finally, a narrative approach can help a child derive their own meaning from their story, by which they may be able to better inform their assent or seek further information. Arthur Frank describes how the interpretation of a story is the mechanism by which meaning is derived. By having their story laid out through narrative, a child will be better able to derive meaning from that story and from their illness. One powerful question to help a child towards this meaning derivation could be "How does this condition make you

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you"? For children with chronic medical conditions requiring recurrent hospitalization or long-term treatment, narrative emplotment could be useful in providing a longitudinal narrative framework for their care.

Narrative's Potential Role in Exploring Future Care Options: Narrative Stimulation of Imagination

A narrative ethical approach benefits from its ability to develop and direct imagination. Pediatricians know the power of imagination in childhood. Direction of imagination involves the provider's contextualization of the disease in an effort to elicit from the child what they think may happen in the future. Just as one may ask a child while reading a storybook, "What do you think will happen next?", similar questions can be used to explore a child's understanding of the consequences of potential choices. For a child who does not want to undergo an abscess drainage, one might employ the questioning strategy of "What do you think will happen if we cut open the abscess? What if we numbed it first? Would the numbing needle hurt more or the knife?" to both help the child imagine the consequences of future actions and to ascertain exactly what aspects of the proposed treatment they may be uncomfortable with. This strategy is more informative for the physician than simply explaining a proposed procedure to the child, as it helps them imagine the future and also lays the groundwork for the physician to clarify the child's misconceptions. Such a narrative strategy further helps the child center themselves in their care and a narrative practitioner would be uniquely suited to help the child further explore how to extract meaning from the options laid before them.

Narrative Role in Resilience Against Uncertainty: Narrative Resiliency

A narrative bioethical approach could further find utility in providing resilience to pediatric patients and families. Several writers have argued for the integration of narrative medicine into the training of pediatric residents and pediatric palliative care providers, arguing that the practice of narrative medicine improves resilience among

providers. The impetus of these writers stems from narrative medicine's particular ability to help providers to tolerate uncertainty⁸⁻¹⁰. The practice of medicine tends towards black and white. As discussed by Simpkin et. al, such tendency towards finding certainty (in a diagnosis, prognosis) likely stems from the senses of vulnerability and ignorance providers feel in the realm of uncertainty. Simpkin argues for training of physicians towards more comfort with uncertainty to avoid the consequences of providers seeking out the black-and-white. Discomfort with uncertainty is not isolated to providers however as uncertainty is inherent to the recipient end of care at all ages.

I argue that narrative medicine's toolset provides the best approach to helping patients tolerate uncertainty, particularly children. Relative to other patient populations, children are particularly vulnerable to the uncertainty of the receiving end of clinical care given the previously discussed cognitive development impeding their full ability to grasp medical dilemmas. Central to the practice of narrative medicine is the understanding that the patient story is unfinished and ever-evolving. Furthermore, the patient story is open to interpretation and the central character's expectations, values and motivations are changing with every new step in the plan of care or disease process. Firstly, a narrative approach is best equipped to identify areas of uncertainty in the patient's story. By using questions similar to those discussed in the above section, pediatricians can explore uncertainty children may have about when their disease began, who the characters in their story are and most powerfully, what the many different next steps may be. Narrative medicine's power is not in resolving this uncertainty in children, but helping guide children towards comfort in their uncertainty as medicine is only equipped to answer so many questions. Narrative medicine unique strength is its ability to find the story, reflect the story and then partner with patients in defining the patient's derived meaning from that story. It is in this meaning-making practice that comfort with uncertainty can find its roots for the plan of care to blossom. While narrative medicine's

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strengths with uncertainty are absolutely not exclusive to pediatrics, it is uniquely equipped to both provide the framework of narrative to the pediatric patient and then explore the uncertainty that still remains.

Conclusion

This piece argues that a narrative approach to bioethics in pediatrics has a large potential to benefit ethical tensions in the clinical care of children while also stimulating resiliency in pediatric patients. While this piece attempts to define several strengths a narrative approach can bring to pediatric bioethics, this list is not exhaustive and the author is hopeful that this piece can drive further work and discussion on narrative's potential in pediatric bioethics.

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2023 BIOETHICS ESSAY CONTEST

2nd Place Winner

The Destination of "Nowhere" Daniel H. Kim, MD, FAAP

Melanie was a beautiful 1-month old girl born with hypoplastic left heart syndrome. She underwent the Norwood procedure, the first step of palliation. Unfortunately, she suffered a cardiac arrest of unclear etiology, requiring cannulation onto venoarterial extracorporeal membrane oxygenation (VA ECMO). Her hospital course was further complicated by kidney failure requiring continuous renal replacement therapy (CRRT). Any attempts to separate off ECMO and CRRT were

unsuccessful. Without ECMO, she quickly became hypotensive and hypoxemic, requiring significant vaso-active support despite optimization of her fluid status and oxygenation. Off CRRT, she developed pulmonary edema and fluid overload. Work-up to delineate causes of her inability to separate from ECMO support were unrevealing. She was evaluated for heart transplantation. Due to ongoing ECMO and dialysis dependency and a

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high degree of human leukocyte antigen (HLA) sensitization, the transplant committee deemed Melanie prohibitively high risk for poor outcome post-transplant and declined her for heart transplant. She was also too small for home-going device like a ventricular assist device (VAD). ECMO was no longer a bridge to recovery or decision, but rather a "bridge to nowhere", -- a "destination" in which Melanie found herself in stasis.

We found ourselves at a crossroads. Melanie was well supported by ECMO and dialysis. However, now that transplant was no longer an option, several questions lingered on the minds of her care team. She was not actively dying, but recovery was extremely unlikely without any options for ECMO separation via transplant or VAD.

Thankfully, Melanie's neurological status remained intact, despite having been on VA ECMO for nearly a month. Melanie's parents would tell me about how she would open her eyes, look at them when they spoke to her, and grimace in annoyance when her dad would sing certain songs while he softly strummed his acoustic guitar. "Her favorite is Simon and Garfunkel", Melanie's dad said proudly. Every day, Melanie's nurses and respiratory therapists would work seamlessly to transfer Melanie into her parents' arms, taking care to account for two large ECMO cannulas, leads, wires, and numerous tubes that tethered her to her intravenous medications. Her family appreciated this undertaking, as Melanie would spend hours sleeping peacefully in her parents' arms. Her parents could not get enough of her.

Facing this impossible situation, Melanie's parents shared conflicting goals and values with the team. They wanted to maximize the time she had to be awake and comfortable, reacting to their touch and voice. They did not want her to suffer, but were not quite sure how to reconcile that with her "bridge to nowhere" status. The team proposed a "time-limited trial" of one week to perform a final ECMO "trial-off" and plan to discontinue ECMO, no matter the

outcome. We chose one week because her ECMO circuit was already on its last legs and we did not anticipate it lasting very much longer than a week. If Melanie's ECMO circuit failed due to clot prior to the one week mark, then the final trial-off would be done at that point without intention to replace the circuit. Her parents agreed.

Quill and Holloway define time-limited trials as "an agreement between clinicians and patient/surrogate decision-makers to use medical therapies – such as mechanical ventilation... or dialysis – over a defined period of time to determine if the patient improves or deteriorates according to agreed-upon clinical outcomes". They proposed a five-step framework for initiating timelimited trials consisting of a meeting between the care team and the patient or surrogate decision-makers to: (1) define the patient's acute care needs and prognosis, (2) clarify the patient's goals and preferences, (3) identify objective markers for improvement or deterioration, (4) suggest a time-frame for re-evaluation of the patient's condition, and (5) define potential actions to take at the end of the trial, or if complications arise during the trial, actions that should be taken.2 Time-limited trials have also been described as "a patient-centered ethical process incorporating the best estimate of prognosis, QoL factors, and patient values".3

Melanie's family asked a question common to time-limited trials, highlighting an important limitation – how do we know the time we chose is enough time? Ultimately, the duration of time chosen for a trial is an arbitrary decision, in this case tied to the expected duration of the patient's current circuit. We could not with certainty say that the one-week deadline we chose would be sufficient time to fairly assess adequacy of Melanie's ability to separate from ECMO or confer a different outcome than the multiple failed trial-offs.

Wightman points out that another concern with a timelimited trial is the difficulty in meeting the requirement for clear, meaningful endpoints. We often utter the

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phrase, "the bridge to nowhere". However, what is "nowhere"? ECMO is clearly successful in meeting physiologic endpoints such as cardiac output, oxygenation, and ventilation. If the circuit remains patent and oxygenator free of significant clot burden, these endpoints will be met and do not serve as adequate discrete markers for determining whether a time-limited trial is successful. Even if a circuit fails, it could—and in other circumstances would routinely—be replaced. Melanie's parents may not agree that this is "nowhere", as time on ECMO represents more bonding time and development of their beloved child, even if the notion of life outside of the hospital is impossible.

The team proposed other endpoints such as serious clinical events associated with ECMO, such as stroke or the inability to come off CRRT. Endpoints such as failure to wean off life-sustaining treatment or evidence of stroke on brain imaging may reflect a technical criteria fallacy. 5 A technical criteria fallacy involves the medicalization of decisions that are inherently value-based.4 Seemingly objective criteria such as the inability to wean off CRRT or stroke implicitly reflect our teams' value judgments of quality of life for someone needing longterm dialysis or living with neurological deficits from stroke. It was imperative for us to share concerns of longterm kidney failure or risk of stroke with Melanie's parents, but also take care not to impose the belief that a life on long-term dialysis or disability from stroke was not worth living by using that as a determination to withdraw life support.

Foregoing of ECMO could be justified by appealing to the ethical principles of non-maleficence and justice.¹ We should prevent further harm and suffering on ECMO. If there is no chance to live off ECMO, then ECMO ultimately is "futile" due to limited utility. Futility is a term fraught with value-laden judgment. We call it futile because we see her clinical course resulting in certain death, thus ECMO serves no purpose except to delay the inevitable. However, others may argue that her ECMO is not futile

because her current level of support is meeting physiologic goals and her current neurological status remains intact and she is spending meaningful time with her family. Justice calls for us to be good stewards of limited medical resources, like ECMO circuits and highly trained staff capable of running the pump. At this time, we were not forced to reallocate a scarce resource, but rather be thoughtful about future needs. This would not serve as sufficient justification to unilaterally withdraw ECMO.

I argue that it was not any of these principles or the results of a time-limited trial that helped Melanie's family decide to forego ECMO, but rather the relationship and trust our team had fostered with them. I believe the time explicitly provided was most meaningful to her parents. They spent more quality time with Melanie, which helped them clarify their own values, which ultimately meant a life free from life-sustaining treatments, and allowed our team to make a recommendation aligned with their goals.

The End

I cared for Melanie over several weeks. With her parents, I celebrated each small win, like when she opened her eyes for the first time in weeks. Even the small setbacks did not seem to faze them. "She's strong. She'll get through this, just like everything else," her mom stated confidently. When Melanie was declined for transplant, I sat with them in silence, the disappointment and sorrow thick and palpable.

At the end of the time-limited trial, Melanie was not able to separate from ECMO. Her parents had time to clarify their values and goals for Melanie. Melanie's dad told me he did not want her to suffer. I asked him what he meant by suffering. "Needing life support with no end in sight," he stated. They would not want her to live indefinitely on ECMO. Naturally, they struggled with the impossible decision to agree on a time for their child to die. She acted like a normal baby, seemingly unbothered by the tangle of lines and tubes in her tiny body.

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I recommended moving to comfort care that day. Their family had gathered from all around the country. If there is one thing for certain, Melanie had spent her short life enveloped in the overwhelming love of her large family, full of laughter and music. That night, her parents spent hours holding her one last time. We turned down the ECMO flows. Melanie died in her mother's arms.

I believe the benefit of a time-limited trial was simply the time given to process the painful news of transplant rejection and the opportunity to gather family members and say goodbye. We gave them the gift of time to spend with their daughter. In time, Melanie's parents were willing to share their values and goals as our care team learned more about her family and deepened trust and mutual respect. They did not want her to suffer on ECMO, acknowledging their feelings of selfishness for wanting to keep her alive for themselves. I assured them that no parent should ever make a choice like this and that it was anything but selfish. I tried to shoulder some of their burden by suggesting her "time to die", feeling the gravity of setting yet another seemingly arbitrary time for finality.

At the end of the night, Melanie's nurse pulled me aside and told me the reason Melanie's parents felt at peace with their decision was because they knew how much I had fought for Melanie, and that I felt this was the right thing to do. The privilege I hold to walk with families in their journey is not lost on me. The "bridge to nowhere" can serve as an opportunity to build relationships and shepherd an end of life that is both peaceful and meaningful.

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2023 BIOETHICS ESSAY CONTEST

Honorable Mention

This Item Is Not Reimbursable Joseph deBettencourt, MD

She arrived by helicopter, in distress. The community hospital had intubated her on the fourth attempt, her electrolytes were deranged and her glucose dangerously low. They sent her to us, "It is the best place for her" they had told her, "They have all the experts there." Our intensive care unit was ready to receive her. When her mother arrived, I wheeled in the custom designed tablet computer and called our video interpreter service. I explained how we were helping her breathe, how we

were giving her fluids, sugar, and salt to her in an IV, how we were starting antibiotics. The interpreter translated for us, "We are going to take care of her." We stabilized her with boluses and drips. In the morning the nurses asked, "can we do anything for this rash?"

The wound care note read like a horror novel, "diffuse areas of erythematous, denuded skin with open areas of

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bleeding." This diaper rash was the real deal. Malnutrition and constant diarrhea had left her skin tender, raw, and getting worse by the day. Fortunately, as a patient at a quaternary care center for children we were expertly poised to care for this battered bottom. Consult requests went out to our specialists: Wound Care Team, Dermatology, and our Nursing skin care assessment team. While we the medical team optimized nutrition the consults crafted a skin care regimen. They signed the note ending their recommendations with, "on top apply a thick layer of zinc barrier cream." Not the simple zinc barrier cream, they opined, but the extra tough stuff: 40% zinc barrier cream, applied like cake frosting. "No additives" the consultants warned, "no additional fragrances" they reminded. Firing up our best-in-class electronic medical record I deftly placed the order from central supply: "WHITE PETROLEUM-ZINC PASTE (40%)". A tube of cream arrived at the unit through the pneumatic tube maze in our hospital's recently renovated walls. "No," said the Dermatologists "look at all the additives! She should use this brand only!" We replied to them deferentially, "Where can we get it?" Their answer, "Her mother could buy it off Amazon for only \$19.28 (shipping is free with Prime)."

Using our 24-7 telephonic interpreting services I called the mother, at home with her other children. I updated her on the ventilator settings, the new enzyme replacement cartridges we had been able to obtain for her feeds (a sample from the company!) and the results from her latest genomic study. I then had one simple request for her, a simple task: some diaper rash cream for her child. Yes, we had some at the hospital (but not the best). She could order some online. Of course, that might be difficult without internet or a credit card, but perhaps she could buy some at the store the next time she has a ride and someone to watch the other children. It is only \$19.99 at Target (plus tax)! Only two hours of work to afford it. Perhaps I could prescribe it to your pharmacy, that is, once your Medicaid gets approved. It might require a prior authorization, but we have a team of nurses at our clinic who can help us if it gets denied. Perhaps our clinic has

some samples left in the back. Don't worry, we can figure something out. I hope your FMLA paperwork goes through soon so you can visit, she is looking much better.

Back in the hospital a surgeon is coming, a specialist, no one else in the entire city can perform the operation that she needs. She is being "optimized" for surgery as we check her electrolytes meticulously every day in our stateof-the-art lab. The wound care notes become repetitive, an afterthought that I don't read, "Recommend additive free zinc barrier cream when available." Her surgery is scheduled for Friday morning. A bag of custom IV fluids are hung providing complete parenteral nutrition the night before. The morning of her surgery is busy, but a medium size tub with a purple top has arrived at her bedside. Labeled with her name, the nurses apply a frosting thick layer before she is bundled up and taken down the elevator to the operating room. The zinc cream had arrived just last night, and shipping was free, because I have Prime.

I can order 40% zinc cream off the internet, because I have a job and a spouse with a job and parents and a daycare to watch our son while we are at those jobs. I can order it because I have a bank account and a credit card. I can get my sons medications because I have insurance. When my son didn't like the taste of the vitamin D supplement our insurance would cover, I bought a better one. I use my supports to smooth out the rough spots in medicine. I buy the better cream; I buy the better tasting iron supplement. At my nationally ranked, state-of-the-art, quaternary care hospital I can order an echocardiogram and have it read by an expert pediatric cardiologist with one order in our EMR "ECHOCARDIOGRAM CONGENITAL COMPLETE". However, I'm waiting for the orders my patients and their families really need. "BABYSITTING" linked to an order for "PARKING VALIDATION" both ordered PRN. I need an order to smooth out the rough spots in medicine. I need to know when I order a medicine to be taken "WITH FOOD" that it can be. If I can order a patient a new cornea, I should be able to order her diaper rash cream. It's only \$19.28 and shipping is free with Prime.

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She is leaving by a taxi, sleeping comfortably. The medical supplies have been delivered to her home. Her new g-tube allows her formula to be delivered to her house. We have arranged follow-up appointments with five different subspecialists and her new primary care provider. Her new insurance will take her to and from. Her medications were delivered to her bedside. Her skin is soft, smooth, and clear. Tucked in to one of her bags of medical supplies sits a jar with a purple top, almost empty. We have taken care of everything, except the things that are not reimbursable.



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Trainee Corner: Building an Ethics Elective for Pediatric Residents By Allison N. J. Lyle, MD, MA, FAAP

Pediatric trainees desire ethics education during their training, but institutions vary in their ability to teach ethics when faced with an already heavy didactic load in a short time frame and frequently changing requirements for graduation.¹ Some pediatric residency programs have dedicated elective rotations to pediatric ethics for their trainees, while others do not. When considering establishing such an elective for pediatric trainees, several components should be considered, based on available faculty, resources, and bandwidth. Components may include readings in classic topics, a case write-up, lectures, or participation on an ethics consult service.

Reading of Key Articles and Presentations

Faculty may recommend a few key pediatric ethics articles to cover the introductory topics and concepts such as assent, the best interest standard, the harm principles, or others, and then add in a few more key articles based on the individual's interests for self-directed learning prior to re-convening a time or two to discuss the readings. Some programs will add a component of a case write-up, book review, or presentation for either journal submission or morning report/noon conference-style presentation to a larger group.

Ethics Committee Participation

Ethics committees generally welcome residents to attend meetings (although they may need to sign nondisclosure agreements prior to joining). If there is a consult service, residents can be involved in ethics consults in order to understand the process and analysis of a real case, but this may be more useful for a pediatrics resident if the consults pertain to pediatric cases.

Other Educational Components

If the institution hosts a bioethics fellowship, certificate program, or graduate degree program, or if the institution has an Ethics Center that hosts lectures, residents may be able to sit in on those as well and join in discussions.

Available Resources

There are a number of freely-available resources for trainees interested in ethics – including everything from podcasts to journals/books and key articles, among others. Depending on the resident's interests, they can use these resources to pick and choose topics that interest them (such as neonatal ethics, transplant ethics, etc.). One of

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those resources is the <u>AAP Section on Bioethics case-based pediatric ethics curriculum</u> (login required). For more resources, please visit: https://collaborate.aap.org/sob/Pages/Resources.aspx

Timing of the Elective

Timing of the elective is also important. Most elective rotations or blocks usually contain a period for jeopardy/backup call and vacation, so in reality, the "month" typically only consists of only two weeks' worth of devoted time. Because time is limited, scheduling an ethics elective during the holiday blocks should be avoided, as many ethics activities (eg committee meetings, lectures, and classes) are not held during the holiday season.

Electives in pediatric ethics have the potential to enhance the educational experience for resident trainees and can be created with a variety of components that take full advantage of the resources available at individual programs to fit their needs. There are also a number of online resources available to programs to help individualize and round out this new educational offering.

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Photo by **Andrew Neel**: Pexels

Now that Everyone Can Prescribe Buprenorphine, Will Anyone? Exploring Barriers to Youth Access to Treatment for Opioid Use Disorder

By Maria Rahmandar, MD, FAAP and Faith Summersett Williams, PhD

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Case:

NP is a 17-year-old female who presents to establish primary care after an emergency department visit following concerns of sex trafficking. During history taking, the patient reports being home for the past month following a few weeks of residential treatment from which she was discharged pre-maturely for fighting. Since being home, the patient reports snorting heroin and smoking crack when she ran away from home. She reports abstinence from opioids for weeks between episodes of using. Her last use was about 2 weeks ago, she denies withdrawals or cravings. She experienced one overdose a few months ago when she mixed heroin with a benzodiazepine. She had never been prescribed buprenorphine or taken it nonprescribed, and she has never been on injectable naltrexone. The patient and family have naloxone nasal spray at home.

Her initial point-of-care drug test was negative for opiates, morphine, methadone, oxycodone and buprenorphine. Her send-out extended screen subsequently returned positive for norfentanyl, a fentanyl metabolite. After discussion of the risks and benefits of medications for opioid use disorder, the patient opted to start extended-release injectable naltrexone after an oral challenge, and her family was supportive.

NP opted not to continue naltrexone and disengaged from care for a few months. Her opioid and polysubstance use increased, with two additional overdoses- one of which was reversed by her family. The patient completed a residential program and was discharged on a sublingual buprenorphine-naloxone taper. In outpatient treatment, using shared decision-making, the patient continued buprenorphine instead of tapering off. However, the patient moved in with family out of state to be further away from triggers and former contacts. Thus, she had to transfer care to an in-state provider since controlled substances could not be prescribed across state lines per regulations at the time.

Discussion:

Background

The landscape of treatment of substance use disorders continues to evolve. A key component of treatment has traditionally involved psychotherapy. Overtime, medications have been developed and studied to augment the therapeutic effect or even serve as treatment themselves. There are three main medications for opioid use disorder (MOUD): methadone, naltrexone and buprenorphine. Methadone is a full opioid agonist used in the treatment of adults, but federal regulations typically restrict methadone for youth under 18-years-old. Naltrexone is an opioid antagonist that is used off-label in youth. Buprenorphine is a partial opioid agonist, which means it has a ceiling effect without additional opioid effect after the ceiling is reached. Buprenorphine is approved for 16years and above and comes in several formulations. Prior to 2023, clinicians were required to undergo specific training and obtain a special waiver from the Drug Enforcement Agency (DEA) to prescribe buprenorphine for OUD to a limited number of patients. However, since June 2023, all DEA registered prescribers can prescribe buprenorphine, the special waiver is no longer needed, and there are no patient limitations.1

The interdisciplinary field of clinical medical ethics (CME) has transformed the nature of medical practice in the United States.² CME redefined the practices and teachings of modern clinical medicine by integrating rigorous ethical decision-making into all aspects of patient care.¹ More specifically, all clinicians (e.g., physicians, nurses, and other healthcare clinicians) should *practice* and *apply* CME in their routine, daily encounters with inpatients and outpatients. While very few U.S. clinicians are formally trained as clinical medical ethicists, all clinicians regularly and routinely apply CME approaches such as truth-telling, informed consent, and confidentiality to care for and benefit their patients. These and other clinical-ethical

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considerations have become a part of required routine medical practice and are now widely accepted as the legal and professional "standard of care" in healthcare. CME has also elevated the therapeutic relationship between the clinician and patient as the heart of medical practice. Through CME's bidirectional model of the clinician-patient relationship, the moral and technical arrangements of medical encounters are determined mutually and autonomously by both patients and clinicians. The patient-clinician relationship creates the situational context for shared-decision making (SDM) in healthcare encounters. CME emphasizes that SDM is a joint endeavor between patients and clinicians and successful application depends on the preference of both patients and providers to engage in this process.

Stigma as a Barrier to SDM in Substance Use Disorders

To this day, substance use disorders are viewed by some as a moral failing. Blame and shame can prevent people with substance use disorders from seeking care, prevent medical and behavioral health professionals from providing care to people with substance use disorders, and produce harmful rules and regulations. Furthermore, the history of oppressive practices as it relates to substance use treatment (e.g., criminalization) exacerbates existing barriers to treatment. The existence of such stark inequities and health disparities caused by biases in treatment for alcohol and substance use disorders is an *ethical* problem as it undercuts the principle of beneficence and is deeply unjust.

These factors may potentially affect SDM through several mechanisms. First, differences based on socialization (e.g., internalization of the norms and ideologies that society places on certain groups based on demographics) may exist in patient preferences for SDM or in SDM understanding or practice, which may influence behaviors and contribute to differential experiences. Secondly, socialization may also impact SDM through its influence

on the patient-clinician relationship. One of the most powerful SDM facilitators is physicians' interpersonal skills, which are essential to establishing meaningful patient-clinician relationships and creating environments for patients to express concerns and play active roles in their healthcare. Therefore, it is important for interpersonal interactions to not be unduly influenced by stigma and history of oppressive practices, which can suppress the patient voice in SDM.

Access & Consent to Treatment with SDM in Pediatric Substance Use

Overdose death rates are rising faster among youth than among adults.³ During the COVID-19 pandemic, deaths due to drug overdose increased sharply across the population, and more than doubled among youth and young adults. 4.5 Access to treatment for opioid use disorder, including medication, is critical to address these preventable deaths. The American Academy of Pediatrics and the Society of Adolescent Health and Medicine advocate for improved access and recommend that adolescents be offered medications for opioid use disorder.6 Despite this strong recommendation—and data to support treatment efficacy—adolescents access medications for opioid use disorder at lower rates than young adults. Providers have cited several barriers, including a lack of belief in buprenorphine treatment (suggesting inadequate education/training), a lack of time for additional patients and concerns about reimbursement/payment.8

Unlike adults, children lack the developmental capacity to make their own medical decisions; for many reasons, our society generally empowers parents to make medical decisions for their children. However, there are several circumstances where parental authority is not absolute. These situations include medical emergencies, emancipated minors, universal mandatory public health measures (such as newborn screening), abuse/neglect, and specialized consent statutes. Specialized consent

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statutes vary by state, but generally give adolescents some autonomy to seek and consent to substance use treatment and reproductive healthcare. Special consent statues aren't necessarily based on the decisional capacity of the minor, but on the belief that requiring parental permission may lead an adolescent to forgo care which has serious personal and public health implications. 9,10,11,12 While parental support and involvement may encourage youth initiation in treatment, state regulations that require parental consent for substance use treatment8 can create barriers to accessing treatment.

Proposed Solutions

Many in the field are working towards solutions to support pediatricians in providing and navigating substance use treatment that respects adolescents' self-determination. Particularly given the increase in overdose deaths for adolescents, there is urgency to equip pediatricians with the ability to prescribe MOUD.

One important step towards expanding access to MOUD was the elimination of the federal requirement for practitioners to obtain a special waiver to prescribe buprenorphine. Despite the removal of the waiver requirement, it remains to be seen if MOUD access will improve, especially for the pediatric age group. Everchanging federal laws as we emerge from the COVID pandemic around telehealth allowances and controlled substance prescribing, along with variable state regulations and hospital/medical group rules about providing care across state lines, create additional confusion, fear and barriers to pediatricians comfort in treatment intiation and maintenance for youth with opioid use disorder, particularly those across state lines.

Strategies to support MOUD practices for pediatricians can include 1) promoting/incentivizing professional training in MOUD, 2) funding consultation services to

assist primary care pediatricians with navigating/ integrating MOUD treatment and substance use counseling resources, 3) embedding adolescent addiction specialists in primary settings, 4) expanding payment plans to include multiple insurance types for clinic reimbursements, 5) providing quality improvement analysis to track and adopt practices as they are implemented, and 6) training in equity based SDM. Ultimately, improving access to substance use treatment for children and adolescents requires a multipronged approach with equity and justice at the foundation, particularly in the context of MOUD among adolescents.

In conclusion, it is imperative that our country changes its approach to youth with opioid use disorder to mitigate its significant impact on lives. We must combat stigma around opioid and other substance use disorders and overcome other barriers to care that limit access to life-saving medications and other recovery services. With the elimination x-waiver, more pediatricians are eligible to prescribe MOUD, but they need additional support in order to do so and meaningfully expand treatment.

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Resources

- Avoiding stigmatizing language: https:// publications.aap.org/pediatrics/article/149/6/ e2022057529/188090/Recommended-Terminologyfor-Substance-Use
- Training to treat opioid use disorder in adolescents: https://www.aap.org/en/patient-care/substance-useand-prevention/training-to-treat-opioid-usedisorder-in-adolescents/
- Treatment locator- SAMHSA's National Helpline: https://www.samhsa.gov/find-help/nationalhelpline

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AAP Sites



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