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

As the end of the academic year winds down and as a new one begins, there is a familiar sight in the halls of the hospital: tour groups filled with the fresh, smiling faces of new trainees. While some lament July 1st with memes and “July Effect” comments, I’ve come to look forward to this time of year.

I love the anticipation and enthusiasm that new trainees bring. These trainees are excited; they are hopeful and idealistic. They are inquisitive. Their energy is contagious—and seeing them softens my jaded heart just a bit. They balance out the sense of loss as our graduates launch into their new careers. New trainees buzz with nervous energy, uncertainty and potential. This moment is a new beginning, but it is also a culmination of the sweat and tears of years of hard work. They’ve finally arrived at their destination.

I also love watching yesterday’s interns become today’s senior residents (and yesterday’s residents become today’s fellows). Seeing their growth over time is rewarding—especially as they often change in unexpected ways. Their first days remind me of my (much more remote) first days—a poignant reminder of the power of a kind word or gesture when one is vulnerable. The first day/new kid experience is universal—we’ve all experienced this at one point in our career.

This time of year always reminds me of the honor it is be a part of our trainees’ journey. In recognition of past, present, and future July 1st, this newsletter features pieces all written by trainees (save the standing columns). It highlights our future colleagues’ pieces and celebrates the unique perspectives that trainees bring to bioethics.

Thank you to all of our authors, to Dr Steve Leuthner, Dr Becky Benson, and Ms Sue Wizniak, and our readers—without you, this newsletter wouldn’t exist! Happy Summer, everyone!
The interaction of medicine, law, and ethics has been around for a long time. When I think back, my interest in these areas began when I took an undergraduate Bioethics elective for one of my philosophy core classes at Loyola University, not long after the Baby Doe legal and legislative changes happened. Familiar to most in the Section are the historic landmark legal cases, such as Cruzan, Quinlan, and later Schiavo. The ethics of these cases have been debated on the national stage, with both the medical and ethics communities participating in these conversations. Often, these dialogues have led to medical and societal changes.

As my neonatal career has developed, I’ve witnessed medical advances that have included lowering the gestational age of viability at the same time that I’ve witnessed the political and legal attempts to restrict abortion. These have included the introduction of the Born Alive Act, the determination that Emergency Medical Treatment and Labor Act (EMTALA) encompasses labor and delivery units, and then attempts of expanded interpretations of Child Abuse and Prevention Treatment Act (CAPTA).

When I reflect on the legal landscape that affects pediatricians today, the case that immediately comes to mind is the recent Dobbs decision, which removed national protections for abortion—leaving decisions regarding protections or restrictions to individual states. Another issue on the forefront of the legal landscape is access to gender affirming care for youth. Here again, state laws impact the care patients receive and the way pediatricians practice.

The attacks on these practice issues within some states challenge the ethical standards of equity and justice. We hear from pediatricians practicing in these states the moral distress they experience in making decisions between providing medically appropriate care for patients (while placing themselves in vulnerable legal positions) versus not providing the care to which they feel their patients are entitled. While the “easy” solution seems to refer patients to a less legally restrictive state for care, pediatricians often feel helpless and at some level feel like they are abandoning their patients. Referral to another state may also seem threatening to a physician. Having these rulings based on state determinations creates functional differences in access to care for our patients as perhaps only those with resources can get the appropriate medical care.

So what can we do to support our pediatrician colleagues who are practicing in environments which potentially jeopardize their careers? In the words of our colleagues at the American College of Obstetricians and Gynecologists: “[Our] resolve is unwavering: we will continue to support our members, our community partners, and all people in the ongoing struggle against laws and regulations that violate and interfere with the patient-physician relationship and block access to essential, evidence-based health care.” We must stand up for equity and justice for patients, support our colleagues through recognition of their moral distress, and at the same time be advocates at the state level in education and conversations as much of these laws are based on a lack of understanding of consequences or disinformation.1,2,3

As this year’s election approaches, I want to encourage all to participate in respectful advocacy and to vote!

References:

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William G. Bartholomew Award for Ethical Excellence
2024 Award Recipient - Brian S. Carter, MD, FAAP

Dr Carter has been selected as the recipient of the 2024 William G. Bartholomew Award for Ethical Excellence. This award will be presented on Sunday, September 29, 2024, at 8:00AM, during the Joint Program (H3003) of the Section on Bioethics, Section on Neonatal and Perinatal Medicine, and Section on Hospice and Palliative Medicine at the National Conference and Exhibition in Orlando, FL.

Dr Carter is a Professor at the University of Missouri at Kansas City School of Medicine (UMKC) with dual appointments in the Department of Pediatrics (Neonatology) and the Department of Medical Humanities & Bioethics. He has been a clinician-educator-researcher in pediatrics, neonatal-perinatal medicine, bioethics, and palliative care. Since joining Children's Mercy-Kansas City in 2012, Dr Carter has been instrumental in shaping the development of the Children's Mercy Bioethics Center, including its Certificate Program in Pediatric Bioethics, and recently has served as its interim director. He has authored over 200 peer-reviewed articles and book chapters addressing pediatric and neonatal care, ethics, and palliative care. He is a contributing author and editor of Merenstein & Gardner’s Handbook of Neonatal Intensive Care, the first clinical handbook on pediatric palliative care (Palliative Care for Infants, Children & Adolescents), and the first clinical handbook of perinatal-neonatal palliative care (Handbook of Perinatal & Neonatal Palliative Care). In 2018, Dr Carter was honored with the William T. and Marjorie Sirridge Endowed Professorship in Medical Humanities & Bioethics at the UMKC School of Medicine. In 2020, he was appointed Chair of the Department of Medical Humanities & Bioethics at UMKC. In 2021, he became the Editor-in-Chief of Clinical Pediatrics. He is a past chair of the AAP’s Section on Hospice & Palliative Medicine. Dr Carter recently received the 2024 Pioneer Award for his innovative pioneering leadership in fetal, neonatal, and pediatric palliative care at the Workshop on Neonatal-Perinatal Practice Strategies, sponsored by the Section on Neonatal-Perinatal Medicine.

He received his medical training at the University of Tennessee, completed his pediatric residency at Fitzsimons Army Medical Center and his Neonatal-Perinatal Fellowship at the University of Colorado Health Science Center. Please join us in celebrating Dr Carter's accomplishments by joining us at the award program at the AAP NCE.
2024 National Conference & Exhibition

Sunday, September 29, 2024
8:00AM-12:00PM (EDT)
Location: Hyatt Regency Orlando, Windermere Ballroom Y

Program: H3003 - When External Factors Limit Options: Caring for Birthing Families (Joint Program: Section on Bioethics, Section on Hospice and Palliative Care Medicine and Section on Neonatal Perinatal Medicine)

Description: When risk for morbidity or mortality in newborns is high, best practice involves shared decision-making. Factors beyond the control of parents or clinicians, including evolving regional resources, institutional policies, and legislation, can limit options offered. Participants will discuss approaches to these scenarios through a multidisciplinary lens.

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<th>Time</th>
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| 8:00 AM | Announcement of SONPM Young Investigator Awards
  Alexis Davis, MD, MS, FAAP
  Sponsored by Reckitt Mead Johnson |
| 8:05 AM | Presentation of William G. Bartholome Award for Ethical Excellence
  Presenter: Steven Leuthner MD, MA, FAAP
  Awardee: Brian S. Carter MD, FAAP |
| 8:35 AM | Introduction of Session
  Moderators: Amy Trowbridge MD, FAAP, Angira Patel, MD, MPH, FAAP, and Brian Hackett MD, FAAP |
| 8:40 AM | Constraints on Available Neonatal-Perinatal Care Options
  DonnaMaria Cortezzo MD, FAAP |
| 9:15 AM | Ethical and Moral Implications of Constraints in Neonatal Perinatal Care Options
  April Dworetz MD, MPH, MA, FAAP |
| 9:50 AM | Update from AAP staff on advocacy for shared decision making and physician support |
| 10:00 AM | Break* |
| 10:20 AM | The Dance of Shared Decision-Making: How Honest Human Connection Can Make All the Difference
  Ashley Waddell Tingstad JD — Courageous Parents Network |
| 10:55 AM | Catalysts and Constraints toShared Decision-Making—Helping Birthing Families Create a Path Forward
  Terri Major-Kincade MD, MPH, FAAP |
| 11:30 AM | Panel Discussion and Audience Q&A
  Terri Major-Kincade, Ashley Waddell Tingstad, April Dworetz, DonnaMaria Cortezzo |
| 12:15 PM | Adjourn |

*This portion of the agenda is not designated for CME credit.
Bioethics Spotlight: Dr Matthew Kirschen on the Revised Uniform Determination of Death Act Project
Porsha Butler, MD, FAAP, Neonatology Fellow (University of Arkansas for Medical Sciences, Little Rock, AR)

Dr Matthew Kirschen is an Assistant Professor of Anesthesiology and Critical Care Medicine, Pediatrics, and Neurology at the Children’s Hospital of Philadelphia. He is the associate director of Pediatric Neurocritical Care at CHOP. His research is focused on using multimodality neuromonitoring to detect and prevent brain injury in critically ill children, predicting recovery in children after severe acute brain injury, and the accurate diagnosis of brain death. He is chair of the American Academy of Neurology (AAN) Ethics, Law, and Humanities committees, a member of AAN’s Brain Death Workgroup, and co-lead author of the 2023 multi-society US brain death guidelines. In this interview, Dr Kirschen details the Revision of the Uniform Determination of Death Act project and his participation in this work.

Would you tell us about the Uniform Law Commission and why the Uniform Determination of Death Act (UDDA) was drafted?
The Uniform Law Commission is a non-partisan group of lawyers, judges, legislators, and law professors, who have been appointed by each state government, to draft model legislation in areas where uniformity in state laws is desirable. The initial goal of the Uniform Determination of Death Act was to have a uniform definition of death across states so a person would not be considered alive in one state and dead in another.

In your opinion, why was a revision to the Uniform Determination of Death Act necessary?
The root of many objections related to brain death revolve around the discordance between the legal definition of death and the medical standards used to determine death. The Uniform Determination of Death Act uses the terms “irreversible” and “all functions of the entire brain, including the brainstem” in its definition of death. In medical practice, this is interpreted to mean permanent cessation of all clinical functions of the brain, including the brainstem. The intended goal of the revision was to bring the law into alignment with current medical practice.

Do you see a significant difference between the legal standard of brain death and the medical standard? If so, do you see that as a serious problem?
The 2023 American Academy of Neurology guidelines, 2023 Canadian guidelines and the World Brain Death Project are all in concordance and state that the medical standard of death is the permanent cessation of all clinical functions of the brain, including the brainstem. Clinical functions of the brain in this context are defined as coma, brainstem areflexia, and apnea. There are some who insist on a more literal interpretation of the Uniform Determination of Death Act and want death to only be declared when there is irreversible cessation of all functions of the entire brain, including the brainstem. This then creates a gap between the literal interpretation of the law and established medical practice. The most common brain function discussed in this context is hypothalamic function. The guidelines do not (and have never) require evidence of absence of hypothalamic function. In clinical practice, this most commonly means that patients can be declared brain dead despite not having diabetes insipidus. Some consider the presence of hypothalamic function as not meeting the threshold for cessations of all functions of the entire brain.

What was your experience/role with the Revision Drafting Committee and why were you selected?
I am a member of the AAN’s Brain Death Working Group and was asked by the AAN to be their pediatric representative to the Uniform Law Commission study and drafting committees on the revision of the UDDA, along with my colleague Ariane Lewis who is an adult neurointensivist and brain death expert. We actively participated in the various committee meetings and provided our medical expertise in pediatric and adult brain death determination. One of our primary roles was educating the non-medical members of the committees about the pathophysiology and procedures for brain death determination.

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In your opinion, what were some of the most challenging obstacles when revising the UDDA?
The most challenging obstacles were the differences in opinions between committee members and observers related to the definition of death, whether consent is required to initiate a brain death evaluation, and whether families should be given the ability to opt out of having death determined by neurologic criteria.

Why, in your opinion, did the Uniform Law Commission ultimately decide to abandon the Revised Uniform Determination of Death Act (RUDDA) project?
The efforts to revise the UDDA were ultimately suspended due to inability to achieve consensus on key issues and concerns related to the ability to establish at the state level.

What was your role amongst the panel which created the pediatric and adult brain death/death by neurologic criteria consensus guideline?
I was one of the co-lead authors and the lead pediatric representative amongst the authorship group.

What do you feel were the biggest changes between the prior pediatric guidelines and the adult/pediatric guidelines for kids?
In the 2023 guidelines, the main changes for children were:

a. Removal of an age-based criteria to determine the observation period between evaluations
b. Lengthening the observation period to at least 48 hours before initiating the brain death evaluation for children <2 years old
c. Clarification of prerequisite conditions
d. Clarification of components of the neurologic examination and procedures for performing the apnea test
e. Modifying indications for ancillary testing, most notably removing the prior recommendation to use ancillary testing in the presence of a medication effect or to reduce the inter-examination observation interval. That interval is now fixed at a minimum of 12 hours.
f. EEG is no longer a recommended ancillary test

Given the new recommendations, do you feel that there will be more consistency in the brain death/death by neurologic criteria evaluation process within and between countries moving forward?
We hope that these updated guidelines will lead to improved accuracy and consistency of brain death determination practices in the US and abroad. It is imperative that institutions update their policies and procedures to be consistent with these guidelines and their state laws. It is also important that clinicians who participate in the brain death evaluation process inform themselves about the new recommendations and use this as an opportunity to educate our multidisciplinary teams, including physicians, trainees, nurses, respiratory therapists, chaplains, social workers, etc., about brain death, the processes for its determinations, and implications of a brain death determination. Institutions should create processes for how they are going to handle objections to brain death evaluation or removal of organ support after death declaration.

Where do you feel further research or attention can be focused when relating to brain death/death by neurologic criteria?
We need to focus on educating medical providers and the public about brain death, its meaning, process for evaluation, and implications. We need further epidemiological data to inform future guidelines to eliminate the possibility of a false positive brain death determination. This data would include determining the optimal observation period after brain injury and before initiating a brain death evaluation and between the two neurologic examinations, optimal pH and PaCO2 targets during apnea testing, predictive models

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Bioethics Spotlight: Dr Matthew Kirschen on the Revised Uniform Determination of Death Act Project (Cont’d)
Porsha Butler, MD, FAAP, Neonatology Fellow (University of Arkansas for Medical Sciences, Little Rock, AR)

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for apnea testing safety, the sensitivity and specificity of various ancillary tests, and development of new ancillary test. The data should be stratified by age and brain injury mechanism to be most informative.

We want to express our gratitude to Dr Matthew Kirschen for sharing his experience and expertise in this area, and to Dr Porsha Butler for writing this piece and to Dr Alex Kon for his mentorship and guidance. We encourage members to contact us (kcurran@uams.edu and rebecca-benson@uiowa.edu) for future topics and interviewees.

Welcome to Pediatrics On Call: a podcast on children’s health from the AAP. Each episode features interviews about new research and hot topics in the field of pediatrics. Hear about the most important innovations in pediatrics, from the people who are behind them. While designed for pediatricians and other health professionals, the podcast will also appeal to parents, caregivers and anyone else interested in the science behind children’s health.

Co-hosts -- pediatricians David Hill, MD, FAAP, and Joanna Parga-Belinkie, MD, FAAP – draw on their expertise and training as physicians, as well as their many conversations with families and their own experiences as parents to inform their interviews.

A special series, “Pathways to Pediatrics,” focuses on AAP leaders and celebrated pediatric authorities as they discuss the childhood experiences and early training that brought them to and through pediatrics. Pediatrics On Call, is giving the medical community just what the doctor ordered. Find the newest episodes at www.aap.org/podcast.

Pediatrics On Call is supported by Johnson & Johnson, the global healthcare company. The podcast is available on Apple Podcasts, Google, Spotify, and wherever podcasts are found.
2024 Ethics Essay Contest Announcement
Heather Stob

The American Academy of Pediatrics (AAP) Section on Bioethics (SOB) and the Academic Pediatric Association (APA) Ethics Special Interest Group (SIG) are pleased to announce the joint Ethics Essay Contest.

CONTEST RULES:
- The contest is open to all residents in pediatrics or medicine-pediatrics, and all pediatric subspecialty fellows (including fellows in pediatric surgery, pediatric psychiatry, and pediatric neurology) in North America. The contest is also open to medical students who have successfully matched in to one of these programs by the submission deadline.
- Essays should be written in a prose format and should focus on the ethical issues that residents and fellows face while caring for patients or conducting research. Possible topics include (but are not limited to) cases or issues related to clinical ethics, research ethics, organizational ethics, public health ethics, or global health ethics.
- Essays should be between 1,000 to 1,700 words. Essays longer than 1,800 words will be disqualified without review. References are not counted towards the word count.
- Essays must be original and unpublished works by a single author. Receiving feedback from mentors is acceptable, but the essay must be the author's own work.
- Essays must be de-identified and HIPAA compliant.
- References to appropriate literature are encouraged. References should be prepared according to the most current AMA Manual of Style (http://www.amamanualofstyle.com).

ESSAY SUBMISSIONS:
Submit essays via the form located at https://www.surveymonkey.com/r/3NPVTZM by Monday, September 16, 2024.

AWARD INFORMATION:
Awards for first, second, and third place will be made. Winning essays will be published in the newsletters of both the AAP Section on Bioethics and the APA Ethics SIG. Contest winners will need to complete copyright release forms prior to essay publication. Additional information regarding copyright will be provided to contest winners.

Winners will be offered the opportunity to read their essay at the Pediatric Academic Societies (PAS) Meeting on April 26-28, 2025 in Honolulu, Hawaii.

CONTEST TIMELINE:
- July 1, 2024 – Contest is Announced
- September 16, 2024 – Essay Submission Deadline
- October 2024 – Essay Review and Scoring
- November 2024 – Participants Notified of Contest Outcome
- November/December 2024 – Winning Essays are Published

ADDITIONAL INFORMATION:
Contact Heather Stob, Program Manager, Child Safety, Health and Wellness at hstob@aap.org.

Three awards will be offered:
1st Place - $500
2nd Place - $250
3rd Place - $50
Restoring Secure Attachment to the Patient-Physician Relationship
Anand Jayanti, MD (Child and Adolescent Psychiatry Fellow, University of Texas at Austin)

At the beginning of the year, our class of child and adolescent psychiatry fellows participated in nonviolent crisis intervention training to help us meet the challenge of confronting an agitated or aggressive patient in a way that is safe for both parties. These principles are in keeping with psychiatry’s general priority to subdue one’s own emotions when addressing the needs of a patient. It is an axiom, for example, that a clinician should withhold details about their personal life unless it is unavoidable or helpful for the patient. The well-intentioned concern is that the session’s purpose would shift to serving the clinician, thereby harming both individuals. There are demonstrated benefits to this approach during acute crises, as we learned in our training this year. But could withholding our authentic selves from patients over the long term deepen their mistrust of their own emotions, as explored in attachment theory? And how does it bode for our own psychological health to sacrifice our authenticity for the attachment we find through our work?

This principle against self-disclosure has even earlier origins than fellowship or residency. Where we are now dedicated to our patients, we were earlier dedicated to our training—first as students, then as residents, where the rewarded behavior was the focus on education and experience, often at the cost of our immediate emotional or physical needs. As a result, we find outlets for these needs or ways to extinguish the anxiety that results from subduing them. During work, we often vent to peers and colleagues, cultivating the sometimes dark humor of nurse stations and break rooms. Those with vibrant lives outside of the hospital may spend time after work with family and leisure activities, but those without such avenues may resign themselves to the depression and anxiety of an increasingly lonely life or succumb to substances or other addictive behaviors.

We appreciate this phenomenon and its consequences and address it by way of limits on working hours and movements like wellness. Nevertheless, clinicians continue to report that they don’t identify with their work as they hoped they would. The changes coming to our field from outside forces like governing bodies and the private sector encourage us to pause and consider where the physician will be situated with respect to their well-being in the coming years and what we must do to move the needle forward.

We may start in the opening chapters of Alice Miller’s The Drama of the Gifted Child, where she forecasts the reader’s realization that they likely chose a helping profession because that is how we earned love as children—by putting others’ needs before our own. This staggering insight does not land as much like an epiphany as it does like a warning: beware that you might be engaged in a masochistic project poorly optimized for the benefit of either party. It is uncertain what this approach will portend for the physician in the course of time, as it is a relatively new profession anthropologically speaking, but we know with certainty that this doesn’t make for ‘the good life’ that we recommend to our patients. We rightly help patients realize when they may be harming themselves in a similar way, often by pointing out that they may also have been rewarded in early life for that sacrifice, helping them to process unconscious feelings about their own emotionally demanding caregivers, and using behavioral interventions to help them see that there are other ways to find love in their relationships. To patients, visits with a physician may represent a few hours each year. To a physician, however, visits with patients represent several hours a day, during which we are immersed in the very practice of self-sacrifice that we dissuade in our patients. If this is the psychological core of burnout, it is the most meaningful target of wellness efforts.

Restoring a more secure attachment between ourselves and our patients begins with pointing out that our training does not on its own produce this misallocation of priorities, but rather enables it, and thereby attracts individuals who are already prone to it via our psychological disposition. In Sapiens: A Brief History of...
Humankind, author Yuval Noah Harari describes psychiatry’s origins and earlier iterations - village elders, clergy, and family structures. In the closing pages of his book, he laments that despite our other avenues of progress, there is no evidence that we are happier than our ancestors. In the case of providers, we may actually be worse off than our ancestral counterparts. Many prospective physicians who interviewed for medical school said that we chose this profession because we wanted to help people. We were then rightly challenged to specify why it is through medicine that we wished to help, rather than through the avenues of pure science, entrepreneurship, or public service, whereupon we most often pointed to a difficult life experience that committed us to a life in medicine. Later in life, some of our cohort woke up to realize either that the profession wasn’t what they expected, or that they were not who they were expected to be when the cards were turned over. In the midst of this existential crisis, the voice of our childhood surfaces: Why am I unable to carry this burden? If I fail, will I no longer be loved?

Current physicians in training should be taught to be whole people in the provision of care, rather than disembodied, stoic, and infinitely resilient in the perception of our patients. Only the sustained practice of authenticity will teach us that we will be loved and that there is no way to fail through expressing ourselves authentically, beginning with grieving over what we may have lost along the way. Attaining and sustaining that progress may require that in the coming years, we develop a more bidirectional, rather than unidirectional, approach to the therapeutic relationship - one that upholds the psychological health of both parties, perhaps by resembling more traditional or ancestral social structures like families or villages. Likewise, attracting individuals who will find productive joy in our field means aligning the incentives away from sacrifice and psychological silence, and towards integrity and psychological vulnerability. This may in turn require modifying the path to becoming a physician, extrapolating the trajectory of the shrinking preclinical curriculum at medical schools around the country, favoring social-emotional intelligence, and recruiting individuals who seek our profession with psychological independence rather than the need to fill an attachment void to the ultimate detriment of both parties.

The theoretical framing of these problems and solutions is only the beginning, but the burgeoning power of technologies like artificial intelligence implores urgency in discovering what defines us as humans, so that we might preserve it - in art, in invention, and crucially, in the patient-doctor relationship.

References


Questions Left Unanswered: A Pediatric Resident’s Perspective
Dilara Onur, MD, MS (Pediatric Resident, University of Washington/Seattle Children’s Hospital)

I get to the hospital and sit at my computer. I collect your numbers, most of which have not changed since your admission months ago. I see you before rounds. You are by yourself, as usual; an iPad facing your crib at all times. I introduce myself to you, though your body does not react to the touch of my stethoscope. Mechanical breath sounds permeate your chest. G-tube feeds gurgle in your belly. I look into your eyes, unsure of what you perceive. Your extremities contractured, but fortunately, today is a good day in regards to your tone. We round. “Nothing to report. Waiting on home health nursing.” The day goes by and repeats itself. Day by day, week by week.

Until it doesn’t. A smoldering infection has disrupted the routine. A disruption you have endured before. But this time is different. You get transferred to the ICU. The inevitable questions get asked by various members of the medical team. “What are we doing for this child?” “Have goals of care been discussed with the family?” “Does the family get it?”

But when I talk with your parents, a new story emerges. One that is not clouded by the sterility of the hospital. You love your older sister, and the way she sings to you before school. You prefer Frozen over Moana. You wiggle when you’re happy, scrunch your nose with displeasure. You interact. You express joy. You express pain.

You are dynamic. Which sparks questions in my mind, about my role as your resident doctor. What defines meaning in life? Is meaning always framed around purpose and action, or can it be approached from the lens of joy and love and spirit? What is a meaningful life for a child? Is it the ability to play? To learn? To imagine? To create? Or the ability to evoke love, form community?

What is a meaningful life for a healthy child? A previously healthy child now diagnosed with cancer? A child dependent on a tracheostomy and ventilator? A child who is non-verbal and developmentally delayed? A child in the foster care system? Does the answer change in these contexts? And if so, who has the power to shape these narrative contexts?

Who defines the meaning in life for a child? At home? In the hospital? Their parents? Their doctor? Their nurse? The child? How are we using these narrative contexts to provide equitable - or inequitable - care to our patients?

Is moral distress defined by our discomfort of the apparent violation to our personal narrative context, or because active harm is being done to a child? Can two narrative contexts co-exist? Can differing narratives intertwine harmoniously?

I am your doctor. Maybe for a day, maybe for a month. These questions go unanswered. Time and time again. Until I come back to the hospital and sit at my computer. Collect your numbers. And round on you again.
You Can’t Leave Yet: Restraint and Seclusion in Pediatric Care
Emily Rosenthal, MD (Pediatric Resident, Oregon Health & Sciences University)

The handoff I received from the Pediatric Intensive Care Unit team was no different than—in a number of ways, heartbreakingly similar to—many of the others from the past week. “Julie is a 17-year-old female, came in with abdominal pain found to have intentional Tylenol ingestion. She presented about 5-6 hours after the event, acetaminophen level was 143 so she was started on the NAC protocol. Alcohol and salicylates were negative, LFTs and INR normal so far. Urine drug screen was also negative. Poison Control is aware. Third bag of NAC should be starting around 7 pm tonight with repeat labs two hours before the third bag finishes. We’ve been advancing diet as tolerated, but she hasn’t taken much PO yet. Any questions?”

“I don’t think so—that all sounds good, thanks.” Good hardly seemed like the right word when faced with yet another teenager who had attempted to kill themself, but with eight other patients on my list, including two I was trying to discharge, there was little space for another response. Between finishing the after-visit summaries and answering pages, I worked on preparing a transfer note. As a bed was still not available by 6 pm, I gave the same sign-out to our night team that I had received earlier in the day, adding that we should get a behavioral hold signed once she arrived to the floor. Though the specifics may vary depending on location and institution, the basic premises of the forms are the same; once signed the immediate response was, “Well, does mom know that means she won’t be able to go to an inpatient program?”

On arriving the next morning, I saw Julie had been assigned a bed and transferred out of the PICU to the floor overnight. When we got to her name on the list, the night team said she was doing well and her abdominal pain had resolved, but they had not been able to obtain a behavioral hold. “Mom just refused to sign it, we tried to talk to her, but she wouldn’t. Sorry about that.”

“No problem, I’ll talk to her about it,” I replied, adding another check box in the column next to her name with the words sign hold beside it. Later that morning, I entered the room ready to discuss the plan with the family. After updating them about her medical status and plan of care, I turned to the issue of the behavioral hold and asked mom her questions or concerns around the idea. At first, she said she had none and was simply not comfortable with the idea of signing the document. I pressed a little harder. “Can you help me understand your hesitation?” She started by saying all her daughter was emotionally capable of at this point was lying in bed, and that Julie was so terrified of needles that there was no chance she would try to run with an IV still in her arm. After going back and forth for another minute, her mom also shared that she personally had been on a psychiatric hold in the past and did not want to subject her daughter to the same. Instead, she offered to be readily available on the phone at any time she left the room and was prepared to give consent to physically restrain her daughter if it came to that, but would not be signing a document beforehand.

Upon hearing this I realized it was unlikely she would ever feel comfortable signing the hold, let alone when meeting me for the very first time. We finished the conversation, and I left the room, feeling dissatisfied but thinking the matter was done. Later that afternoon, I was on the safety huddle—a call with nursing staff, pediatric residents, and the psychiatry team for all patients thought to be at high risk for behavioral escalation—discussing Julie and shared that a behavioral hold had not been signed. The immediate response was, “Well, does mom know that means she won’t be able to go to an inpatient program?”

As I had only been cross-covering that weekend, I never learned if the family ultimately signed the behavioral hold and whether Julie was discharged home or to an inpatient psychiatric bed. Her situation, however, was one I continued to think about for many weeks after.

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logic of requiring families to sign a hold prior to admission to an inpatient program certainly made sense—for inpatient psychiatric care, during which families are not constantly present (as often is the case during hospital admissions), there needs to be a way of keeping teenagers in the care they need but may not want. And yet, I couldn’t help but feel that this was being used as a bargaining chip. As often is the case in medicine, it felt like there was little space for nuance, and instead, our protocols were butting up against a family’s wishes. How were we supposed to respect this mother’s personal trauma and her own experience with the healthcare system when we were telling her that for her daughter to get a certain kind of care, she needed to sign a form that so vividly reminded her of her past? And what was I supposed to tell my fellow residents if Julie tried to leave or even ended up harming herself again while under our care? In the past, I had cared for another patient admitted for suicidal ideation that our security team had to forcibly tackle to prevent them from jumping off the parking garage roof. With these protocols in place, it seemed impossible to reconcile our concern for this patient with her mom’s experience of being involuntarily (and in her view inappropriately) restrained.

The cornerstones of healthcare bioethics—autonomy, justice, beneficence, and non-maleficence—require special interpretation when applied to pediatrics, as autonomy is understood in the context of the family rather than the individual patient. Ethical dilemmas arise when there are conflicting beliefs about what the best course of action is, as none of the available choices are able to adequately respect all four of these principles. Using coercive measures such as restraints and seclusion, or even restriction of social media (which can be viewed as a form of seclusion) is one such dilemma, as autonomy, beneficence, and non-maleficence are in conflict. For a patient with active suicidal ideation, freely leaving the hospital could easily result in further harm or even death. However, many young adults who were interviewed about their experience of being restrained as an adolescent described nightmares, intrusive thoughts, avoidance behavior, and an exaggerated startle reflex, sometimes as long as five years after their initial experience. Additionally, there are times where these control measures such as restraint and seclusion are used not just for crisis management, but also as an authoritative intervention to reinforce or establish a power dynamic and hierarchy. Given this, it certainly becomes hard to fault parents like Julie’s mother who express hesitation at the idea of granting a healthcare team permission to use such interventions on their child.

Healthcare providers also generally find the experience of restraining (via either chemical or physical means) or secluding patients to be an emotionally challenging and ethically fraught situation. One of the most troubling moral dilemmas for nurses is involuntary medication administration, and providers recognize these crisis situations as some of the most universally high risk both for patients and for the healthcare team. However, restraint is still typically viewed as legitimate even though it is distressing, as there is a sense of obligation to provide care for patients. While adolescents often have capacity and their assent should be obtained for medical care, even if they cannot legally consent, there are times their capacity may be diminished due to a distorted cognitive state; in these circumstances there is a duty of care. Yet that duty of care does not mean the medical team can fully dictate management. They are obliged to simultaneously protect the right of the patient to adequate and age-appropriate care, as well as the right of that child for protection against harm. When the care provided is also a threat, however, the healthcare team is placed in a uniquely challenging situation where it can feel impossible to satisfy both of those rights.

Ultimately, Julie’s situation was a powerful reminder of the potential trauma our therapies can inflict upon patients and their families even while keeping our patients safe. Undoubtedly, we will continue to encounter dilemmas...
You Can’t Leave Yet: Restraint and Seclusion in Pediatric Care (Cont’d)
Emily Rosenthal, MD (Pediatric Resident, Oregon Health & Sciences University)

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such as this where we are unable to fully satisfy all the
tenets of ethical decision making. I hope, however, that
when those situations arise I am able to appreciate the
nuance of those circumstances and move beyond
protocols already in place to work with families, rather
than feeling trapped in a struggle against them.

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Nominations are being sought for an award to recognize an individual impacting public discussion of ethical issues in pediatric medicine. The award will be presented to a Fellow of the American Academy of Pediatrics (FAAP) or another individual who has made a significant contribution to the field. For a list of past winners visit: AAP Collaborate/SOB/Bartholome

The award recipient will receive a plaque, honorarium, and reimbursement for expenses to attend the Section on Bioethics program at the AAP National Conference and Exhibition. The recipient will be asked to briefly address the members of the Section on Bioethics at the time of the award presentation.

To be considered for the 2024 award, nominations, and supporting material(s) must be received by September 6, 2024. Nominations should be filled out using the Survey Monkey Questionnaire and be prepared to include the following information for the nominee:

- Name
- City/Town
- State/Province
- Email Address
- Phone Number

- The reason/explanation for your nomination.
- Upload the *Nominee's bio sketch (up to 250 words maximum)
- OPTIONAL: Upload *Letter of Support (up to 2 will be accepted)

If you have any questions (*or have issues uploading the bio sketch or optional letters of support), please feel free to contact Anjie Emanuel at 630/626-6479 or aemanuel@aap.org. Thank you for your input.

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