



Pediatric Ethics Committee

NEWSLETTER

Summer 2022 | Issue 3

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ON TOPIC

DISCLOSING DIFFICULT NEWS TO PEDIATRIC PATIENTS

By Christine Mace, MA, CCLS

At times, in the course of caring for pediatric patients, difficult, life-altering, even terminal diagnoses happen. In those moments, parents are faced with what seems like an impossible question – what and how much should their child know about what is going on within their bodies and how it will impact their lives? This question may come into play when deciding whether to tell the child the name of the diagnosis, what the prognosis is, whether she or he will survive, or even simply the details about necessary tests and procedures.

*“I don’t want my child to know he has cancer.
It will be devastating.
He won’t be able to handle it.”*

For medical providers, telling the truth is an important obligation. It is a way to show respect for the autonomy of patients and to maintain trust. Even for pediatric patients, there is an expectation that providers will seek assent for many interventions to whatever extent the patient’s age and development allow. Yet when patients are under the age of 18, how much autonomy do they have? To what extent should parental wishes to withhold medical information from their children limit discussions with pediatric patients about their care?

The role of a parent is to protect, nurture, support, and educate their child. Parents want their children to have healthy and joyful lives. When that reality is shattered by an illness, it is natural for parents to look for ways to minimize or eliminate any harm that their child will experience

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ON TOPIC *(Disclosing Difficult News To Pediatric Patients continued from page 1)*

It is not uncommon for parents to modify a child's environment to create safe and navigable situations. This, after all, is their role. Most parents would rather swap places with their child than have them go through something difficult or traumatic. They suffer when their child is in pain or is emotionally struggling. It is ultimately out of love that parents would contemplate withholding information from their child. However, could doing so actually cause harm to the child?

Through my many years working in healthcare as a child life specialist, I have counselled parents about how to prepare their children for procedures, diagnoses, and difficult conversations. Parents want to do the "right thing," but they are often not sure what that may be. Parents may project onto their child their own personal perceptions of what the information means and respond, "We can't tell them that! That is too scary! Just the telling of it will traumatize my child." Some parents feel that the trauma of telling the truth could be worse than the pain and trauma of the actual diagnosis or treatment.

This reaction is understandable. Words carry more than their dictionary meaning. For example, *surgery* can mean scary anesthesia, cutting, and pain, not just "fixing"; *cancer* may mean hair loss, fighting for your life, and possible death, not simply a cluster of cells gone awry that needs to be kept at bay. Our



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ON TOPIC: *Continued on page 3)*

Moral Distress Clinical Pathway on EPIC

There is now a clinical pathway entitled "Ethics Consult & Moral Distress Guidance: Pediatrics" available on EPIC that can be used as a resource for situations in which providers are feeling uncomfortable with a patient's care. It will guide you when considering which services might be helpful to address and hopefully resolve the moral distress. To access this clinical pathway, once in a patient's chart, click on the "Pathways" tab at the top of the EPIC screen (the one with a blue box symbol), then choose your patient care unit, and look for the title for the pathway above. Once in the pathway, it's easy to scroll through and click on the links for the information about how the different groups can help and how to contact them.

ON TOPIC: *Disclosing Difficult News To Pediatric Patients (continued from page 2)*

life experiences give connotations to words and phrases that can be far more meaningful to us than their denotations. Certainly, parents are in the best position to know and understand the maturity of their children, past life experiences they've faced, and how they've handled confronting difficult news before. It makes sense that shared decision-making between parents and care providers is a helpful way to explore how and what to disclose. Harm, however, comes in many forms, and completely withholding information from the pediatric patient may cause psychological, emotional, and physical harms itself. Paradoxically, in seeking to keep a child from harm, parents may inadvertently cause harm.

“Disclosing difficult news may, likewise, bring unexpected benefits. A child, like an adult, needs time to process difficult information. Loved ones and trusted care providers may provide context and support as children navigate through emotions and integrate the experience of pain with their understanding of their life and their future.”

Disclosing difficult news may, likewise, bring unexpected benefits. A child, like an adult, needs time to process difficult information. Loved ones and trusted care providers may provide context and support as children navigate through emotions and integrate the experience of pain with their understanding of their life and their future. Knowing about a terminal illness or one that will rob them of certain aspects of their life may allow a teenager the opportunity to mourn, to create experiences with loved ones, to fulfill goals while still able, and ultimately to prepare themselves for what is to come. It opens the door to developing coping strategies for both the child and the parent. Even amidst the helplessness, confusion, and uncertainty there may be opportunities for empowerment.

More often than not, in my experience, teenagers already have a good sense of what is going on before the disclosure. They may not be able to name the illness, but they likely know that

something is very wrong with their body and they may have fears that can greatly intensify and cause suffering without being given the right information. And it is certainly better for the child to receive correct information, to learn about what is happening from care providers and parents rather than looking up on the internet words from conversations that are overheard. We have an opportunity in partnership with parents to help a child's health journey be the most positive and affirming journey it can be. Disclosure allows parents and children to maintain trusted and meaningful relationships from which they can draw strength together and better face what is to come.



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DEAR ASCLEPIUS*

An ethical advice column

**Greek god of medicine and wielder of the famous rod*

DEAR ASCLEPIUS:

Recently, I had a situation where the parents of a kid I was helping take care of asked for us to give the child a medication that I didn't think was indicated. It wouldn't help the kid's medical condition and, as we all know, there could be side effects too. Even after we explained this to the parents, they got really upset when we told them we didn't want to do it. I know that we're supposed to listen to parents as the experts for their child, but in this situation, I wanted to say no. Can we ever say no to parents? When is that OK? Thank you for the guidance,
Family-centered Confused

DEAR FAMILY-CENTERED CONFUSED:

It sure sounds like a difficult situation. You're right that parents should be considered experts on their children; however, medical professionals such as yourself are the experts on illnesses and how to treat them. Proper shared decision making relies upon both voices being heard and considered. There is a long history of parents being given the authority from a legal and moral standpoint of being able to make medical decisions for their children. Parental authority, though, is not absolute. There may be times when clinicians need to override the wishes of the parents. It doesn't happen often, but it can be considered in situations when the parents' decision would unnecessarily put the child at significant risk of serious harm. Whether to say no will depend upon whether and how likely the intervention (in this case, the medication) can achieve the desired goal balanced against the level of the risks that are reasonable to consider. If you and your clinical team think that there is no possibility of benefit in giving the medication and that the drug has potential side effects, then it seems reasonable to withhold that intervention even over the objections of the parents. Through open and respectful conversations, hopefully you'll be able to understand what led to their decision and be able to address their underlying concerns or beliefs as part of redirecting them to more appropriate ways to treat and comfort their child through this difficult time.

Sincerely,
Asclepius



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Photo by [Muhammadtaha Ibrahim Ma'aji](#) on [Unsplash](#)

To submit a question for future "Dear Asclepius" columns, fill out the anonymous [submission form](#). If applicable, remove any identifying patient info before submitting your question. If your question is urgent, do not submit it here. Contact the ethicist on call at your respective location at **785.4651** as well as online: ynhh.org/patients-visitors/patient-rights-responsibilities/ethics-committee

FROM THE CASE FILES OF THE YNHCH PEC *SHOULD VACCINATIONS BE FORCED?*

THE CASE

The patient is a 12-year-old male with disruptive mood dysregulation disorder and autism who was admitted for inpatient psychiatric care after he threatened to harm himself. The care team has recommended a residential treatment program that would offer the patient excellent resources and opportunities for life-skill practice to optimize his chances of transitioning successfully back home. The program, however, will only accept the patient if he receives the MMR vaccine, which his mother has declined on the basis of personal religious beliefs. The care team consulted the Pediatric Ethics Committee to determine whether it would be ethical to vaccinate the patient against the wishes of his mother to enable him to enter the residential treatment program.

DISCUSSION

In the United States, respect for religious freedom has deep historical roots. The Free Exercise Clause of the First Amendment to the US Constitution protects the right of citizens to practice their religion freely. Title VII of the Civil Rights Act of 1964 further protects workers from discrimination on the basis of religion. Significantly, these protections extend to beliefs based on personal religious interpretations, even when those interpretations differ from the teachings professed by a person's religious tradition. When religious practice comes in conflict with the freedoms of others, however, the law is less clear—and in medical ethics, the right to receive religious exemptions for vaccination against pathogens that can harm other vulnerable people remains contentious. As the COVID-19 pandemic has demonstrated, the vaccination debate probes the limits of religious freedom in the face of threats to public health. It is an extraordinarily fraught debate.

In the case of this patient, while decisions to decline the MMR vaccine do collectively have an impact on public health, the primary question before the Ethics



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Committee was not about possible harm to the common good. Rather, it was about possible harm to the patient himself: the patient's vaccination status was an obstacle to his access to the most effective therapeutic option for his psychiatric recovery. The residential program would offer this patient resources he could not experience in the hospital—opportunities to practice building crucial life skills and bridges to independence that would boost his success in his transition back to his home and community. Yet the program was unwilling to accept any religious vaccination exemptions.

Despite the benefits the patient could receive if he were to be vaccinated against MMR, the Ethics Committee identified three primary reasons that it would be unethical to override the patient's mother's religious objection to the vaccine.

***“When religious practice comes in conflict with the freedoms of others, however, the law is less clear—and in medical ethics, the right to receive religious exemptions for vaccination against pathogens that can harm other vulnerable people remains contentious.*”**

CASE FILE: *Continued on page 6)*

First, although the residential program was the most beneficial treatment option, it was not the only treatment option, nor was the program essential to his recovery. The patient could continue to receive care in the hospital followed by intensive outpatient treatment from home, a slower and less comprehensive but nevertheless therapeutic option that would not require the patient to be vaccinated. Second, even in the case of an emergency, for example if the patient's condition were to worsen to the point that he required emergent transfer to a facility that would not accept him without the vaccine—a situation in which life-saving measures might otherwise be considered against parental objection for the wellbeing of the child—the vaccine would not, in itself, be the life-saving measure. It is therefore difficult to imagine even an emergency situation in which it would be ethically permissible to mandate vaccination against the wishes of the mother. We would hope in such a case that the residential program might be willing to consider an exception to their vaccine policy, especially given the unlikelihood that the patient would have

undiagnosed measles, mumps, or rubella after his long period of observation in the hospital. Third, in this case the patient himself shared his mother's beliefs and did not wish to be vaccinated. Had he disagreed with his mother and had he himself wished to be vaccinated for the purposes of admission to the residential program, further discussion with the patient and family would be warranted to determine whether the patient could pursue vaccination as a minor against his mother's objection.

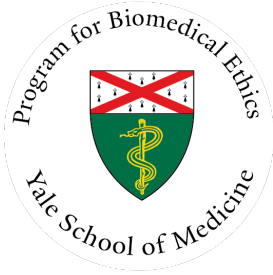
CONCLUSION

The Committee advised that it would not be ethically permissible to override the family's religious objection to the MMR vaccine even to enable entrance to a more beneficial treatment program.

The Committee recommended that the team continue to pursue alternative residential programs that might accept his vaccination exemption. Ultimately, the care team located another residential program that would accept him without the MMR vaccine, and the patient was transferred successfully.



Program for Biomedical Ethics (PBE)

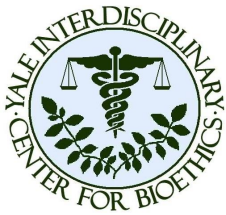


The Program for Biomedical Ethics at Yale School of Medicine serves as a nexus for a community of individuals from throughout the medical campus and beyond who share a common interest in education, research, and clinical practice in the field of medical ethics. The Program for Biomedical Ethics at Yale School of Medicine and Yale Pediatric Ethics Program provides multidisciplinary leadership regarding the ethical and social aspects of health care and medical research. Ethics consults may find their weekly ethics symposia helpful and educational.

For a list of upcoming seminars or to learn more:

<https://medicine.yale.edu/education/ethics/>

Yale Interdisciplinary Center for Bioethics (YICB)



The Yale Interdisciplinary Center for Bioethics is an academic research center based primarily in the study of biomedical ethics. The center sponsors a wide range of university seminars and conferences.

Learn more at: <https://bioethics.yale.edu/programs>

Pediatric Ethics Committee Recent Publications

[Ethical considerations in the use of artificial womb/placenta technology.](#)

Werner KM, **Mercurio MR**. *Semin Perinatol*. 2022 Apr;46(3):151521. doi: 10.1016/j.semperi.2021.151521. Epub 2021 Nov 9. PMID: 34893338

[The Case for Ethical Efficiency: A System That Has Run Out of Time.](#)

Havlik JL, **Mercurio MR**, Hull SC. *Hastings Cent Rep*. 2022 Mar;52(2):14-20. doi: 10.1002/hast.1351. PMID: 35476354

[Priorities, Professional Humility, and Communication in the Setting of Medical Uncertainty.](#)

Mercurio MR. *Pediatrics*. 2022 Jun 1;149(6):e2022056737. doi: 10.1542/peds.2022-056737.

Lori Bruce & Jennifer L. Herbst (2022) [Extending Trauma-Informed Principles to Hospital System Policy Development](#), *The American Journal of Bioethics*, 22:5, 65-68, DOI: 10.1080/15265161.2022.2055210

Benjamin Tolchin, Lori Bruce, Mark Mercurio & Stephen R. Latham (2022) [A Hub and Spoke Model for Improving Access and Standardizing Ethics Consultations Across a Large Healthcare System](#), *The American Journal of Bioethics*, 22:4, 42-45, DOI: 10.1080/15265161.2022.2044551

About the Pediatric Ethics Committee:

The [Pediatric Ethics Committee of Yale-New Haven's Children's Hospital](#), chaired by David Hersh, MD, PHD, serves in an advisory capacity only. The program educates clinicians, staff, residents and medical students on issues related to pediatric ethics and provides consultation services about ethical issues regarding clinical practice related to pediatrics to patients, families and staff. It does not have the authority to determine patient care. It can assist in cases of ethical conflict by offering clear recommendations and ethical guidance. *Some situations in which the PEC can be helpful:*

- Facilitating conversation between patients, parents, and care team members in cases of disagreement about treatment
- Elucidating the significance of personal values, including religious beliefs and cultural traditions, in healthcare decision-making
- Clarifying and articulating goals of care in complex cases
- Supporting patients and parents in end-of-life discussions
- Addressing questions about decision-making capacity and adolescent autonomy
- Addressing concerns about moral distress among care team members
- Responding to ethics worries early to help them from becoming more difficult ethical dilemmas

How to Contact the Pediatric Ethics Committee:

Ethics consultations can be requested by the patient, family, friend, clinical staff and research staff at Yale-New Haven Hospital. **Contact the Pediatric Ethics Committee at 203.785.4651 or 203.747.9144.**

Pediatric Ethics Committee Members

The Pediatric Ethics Committee consists of physicians, nurses, clergy, medical ethicists, community members and others, with considerable experience consulting in matters related to the ethical issues regarding clinical practice related to pediatrics .

Jane Abbottsmith, MD/PhD 2026 (*Assistant Editor*)

Prasanna Ananth, MD, MPH

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Deb Armitage, BS

Elizabeth Berman, JD

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Anna Zhao, YSM MD 2022

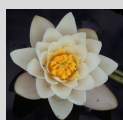


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