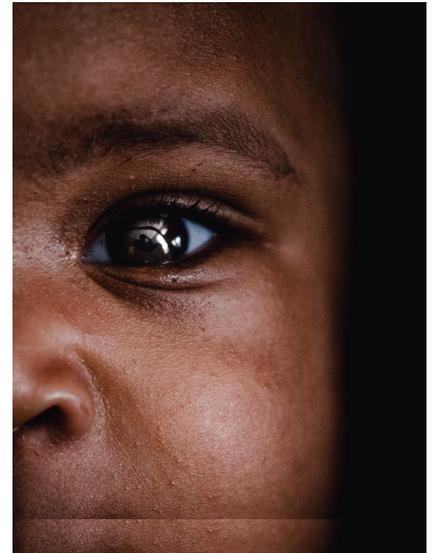


Pediatric Ethics Committee



NEWSLETTER

Fall 2020 | Issue 1



ON TOPIC

How should hospitals make ethical triage decisions for pediatric patients during COVID-19?

Social distancing and isolation measures are proving successful in flattening the curve of the COVID-19 pandemic and have spared Yale-New Haven Hospital from implementing triage protocols designed to ration mechanical ventilators in the case of shortages. Our hospital remains ready, however, to respond in the event of future shortages. How should hospitals make triage decisions? Here are a few considerations.

What factors should go into assigning scores? To ensure fairness, scores should begin with standardized, objective measures of organ function to determine the survival prognosis of each patient. It is appropriate to include some subjective measures, such as clinical impression or treatment trajectory, in fine adjustments to the final score, in order to give a fuller clinical picture of the patient. But just as significant as the list of factors that go into determining the triage score is the list of factors that are completely irrelevant to it. Race and ethnicity, gender and gender identity, sexual orientation, religion, legal status, wealth or “VIP” status, and disabilities that do not affect survival should play no part in triage protocols at any hospital. It would be morally impermissible to base treatment decisions on factors like these.

What to do in the case of a tie? While age is sometimes used to break ties between adult patients, for pediatric patients a lottery is usually the fairest way to break a tie.

Who should make scoring and treatment decisions? Ideally, an independent triage committee should carry the burden of scoring so that bedside teams can focus on advocating for their patients without competing concerns about the allocation of resources in the system. Decisions about who to treat first during situations of scarcity are perhaps the most ethically and emotionally fraught decisions for healthcare workers. The goal of triage protocols is to guide these decisions in a way that is fair—to allocate care first to the patients who are most likely to benefit so that the limited resources may be used to their maximum helping potential.

CASE FILES

May the care team override parental refusal of palliative pain medication for a child who is suffering?

This is the inaugural edition of Case Files. Each quarterly newsletter will feature a YNHH case that presented an ethical difficulty to the pediatric care team, patient, or family and prompted an ethics consult with the Pediatric Ethics Committee. NOTE: These are based on real cases and details have been altered to protect patient privacy.

THE CASE

The patient is a 14-year-old female who is terminally ill from a brain tumor, blind and non-communicative. She has failed all attempted therapies and has a prognosis of days to weeks. In the hospital, the care team believes she is in severe pain on the basis both of visible signs, such as sporadic grimaces and yells, and of accompanying elevations in heart rate and blood pressure. They would like to increase her pain control through the use of opiates to alleviate her suffering, but her parents have resisted due to worries that the opiates will depress their daughter's breathing and make her sleepy. The care team unanimously believes that failing to treat the patient's pain medically would mean allowing her to experience significant and avoidable suffering and would be morally wrong. An ethics consult was requested by the care team to determine whether they may use opiates to treat the patient's pain over the objections of her parents.

DISCUSSION

From a legal and ethical perspective, parents or legal guardians hold authority in making healthcare



decisions on behalf of their children. Parental authority, however, is not absolute and may be overruled in rare

circumstances. The standard traditionally employed in determining the threshold for overruling parental decisions is the best interests standard. This approach demands that surrogate decision-makers must act according to the patient's own wishes or, if the patient cannot communicate those wishes, what they believe to be in the best interests of the patient. For children, who may never have been capable of communicating mature wishes, the best interests.

standard may be a helpful guide for the decisions of parents and care teams.

One difficulty in relying on this standard is that differences in values, beliefs, and experiences may lead to disagreement over defining benefits and harms as well as their relative importance and determining which outcomes are most desirable. In the case of this patient, both the care team and the parents sought to act in the best interests of the child: the parents by helping her to remain as alert as possible, and the care team by seeking to alleviate her significant suffering.

More recently, the ethical literature has shifted from discussions of best interests to discussions of harm. The harm principle, as it has come to be known, dictates that parental decision-making may be overruled if it poses harm above a certain threshold to the child. Though there may still be some debate about what constitutes harm, it is often a more fruitful debate that illuminates common ground. With regard to pain management in particular, physicians have a duty to alleviate pain and suffering to the best of their abilities, especially amongst vulnerable patients. Critically ill children and patients who cannot advocate for themselves depend on the care of those trained to treat their symptoms at the end of life.

During the ethics consult, the parents, who loved their daughter, expressed at the outset their continued hope for a miraculous recovery. They also communicated a fear of opiates that is not uncommon among patients and families: the fear that opiates will dangerously depress respiratory function and hasten death. In the course of

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DEAR ASCLEPIUS*

An ethical advice column

*Greek god of medicine and wielder of the famous rod. 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. Dial the ethicist on call instead at 203.747.9144.

FEAR OF REACHING OUT STYMIES CARE TEAM'S RELATIONSHIP PROSPECTS:

DEAR ASCLEPIUS: As a healthcare worker, I am part of a wonderful team of physicians, nurses, PCA, PAs, social workers, chaplains, and volunteers who are committed to caring for patients. There is one person I am having trouble connecting with, and I'd like your advice about how to improve our relationship: the pediatric ethicist. He or she is always in the hospital



but never seems to notice me. Every so often a complicated case comes up that would be a perfect opportunity to reach out, but I'm afraid to

make the first move. I don't want to seem desperate and I'm worried my other team members will be jealous. I know we would work well together, and our relationship could do a lot of good for patients. Do you have any advice? --HOPEFUL IN NEW HAVEN

DEAR HOPEFUL: Full disclosure—as a representative of the Pediatric Ethics Committee, I have a vested interest in this question. You should feel reassured the ethics committee would be delighted to receive your call. It is staffed 24/7 by an ethicist on call who can respond to immediate questions and convene an ethics consult for further guidance. Anyone can reach out: nurses, physicians, social workers, chaplains, volunteers, patients, families, friends; the PEC listens to everyone's voices. I encourage you to get in touch with even small worries about what is right and good in the care of your patients. Sometimes talking through these questions early can help prevent more difficult ethical problems from developing. Note: the PEC serves in an advisory capacity only: it does not have authority over patient care and only offers clear recommendations and ethical guidance to assist your decision-making. The next time you encounter a complicated case, call the PEC: 203.747.9144.

(Continued from previous page: *CASE FILES: Palliative*)

multiple conversations, the care team was able to communicate that more conservative pain management techniques were not proving effective and not fulfilling the patient's right to relief from suffering. They noted that the feared effects of opiates only occur at very high doses, and that opiates have in fact proven to ease patient respiratory function at the end of life by mitigating air hunger. They also articulated all of the indications they observed of the patient's pain, such as her elevated blood pressure and heart rate, that the parents had previously not appreciated in their own assessment of how much pain their daughter was experiencing. Finally, the team offered difficult but necessary clarification about the patient's inevitable death and the importance of reframing hope and redefining the goals of care in the context of her final days.

CASE RESOLUTION

The ethics committee determined that it was unethical for the parents to reject treatment for severe pain in a terminally ill child. The patient's pain was causing significant harm and the committee advised that it was ethically permissible for the care team to administer the medications they deemed would make her as comfortable as possible to ease her last moments, even over the objections of her parents. The parents ultimately understood that their daughter was suffering and agreed to medical pain management. They remained by the patient's side in the hospital during her final days, and she died peacefully two weeks later.



LITERATURE

Diekema, Douglas S. (2004). "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention." *Theoretical Medicine* 25: 243-64.

Blinderman, Craig D. (2011). "Do Surrogates Have a Right to Refuse Pain Medications for Incompetent Patients?" *Journal of Pain and Symptom Management* 43.2: 299-305.

ABOUT THE PEDIATRIC ETHIC COMMITTEE

Chaired by David Hersh, MD, PHD, the PEC serves in an advisory capacity only: it does not have the authority to determine patient care but 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

Committee Members

Jane Abbottsmith, MS2 (MD/PhD program)

Prasanna Ananth, MD, MPH

Jennifer Papa, RN

Deb Armitage, BS

Lori Bruce, MA, MBE

Laurie Cardona, PsyD

Alison Cubbellotti, RN

Stephen Douglas, MDiv

Matthew Drago, MD, MBE

Mary Lou Gaeta, MD, JD

Chelsea Hartman, MD

Jennifer Herbst, MBIO, JD

David Hersh, MD, PhD

Katherine Holmes, MSN

Karen P. Kolb, APR

Gary Kopf, MD

Stephen Latham, JD, PhD

Christine Mace, CCLS

Kathryn McVicar, MD

Mark Mercurio, MD, MA

Connie Nicolosi, MSW

Samantha Palmaccio, MD

Jeannine Rockefeller, APRN

Anna Zhao, MS2 (MD program)

CONTACT US

The Pediatric Ethics Committee (PEC) is a multidisciplinary group composed of physicians, nurses, APPs, clergy, social workers, child life specialists, and members of the community. Its mission is to provide ethics consultations in difficult cases in order to assist in patient care, to educate the YNHH community about medical ethics in the care of pediatric patients, and to inform hospital policies that affect patient care.

Anyone, including hospital staff, patients, families, and friends, is welcome to contact the Pediatric Ethics Committee: 203.747-9144.