

Pediatric Ethics Committee



NEWSLETTER

Spring 2021 | Issue 2

ON TOPIC

When patients and families are hoping for a miracle

Written by: Stephen Douglas, MDiv, Hospital Chaplain, YNHH



It's a phrase that is often repeated by healthcare professionals with a degree of resignation or dread: They're hoping for a miracle. And I understand why. Work in a hospital long enough and you'll encounter a scenario where the team and the family have intractably different stories about the patient's illness and outcome, and sometimes these cases end in a way that no one would have wanted. The distress that healthcare workers feel in these instances comes not only from the moral distress of feeling helpless or complicit in a care plan that goes against their own ethical compasses, but also out of concern for the patient or family's long-term coping: They are counting on a miracle. What will it mean for them if it doesn't come? Healthcare professionals frequently report feeling uncomfortable discussing a patient's religious and/or spiritual beliefs with them. In one study among medical residents some of the most frequently listed reasons for discomfort included lack of training in discussing patients' beliefs and values, feeling it was outside of their role as physicians, not wanting to impose their own beliefs, and not wanting to disrespect a patient's beliefs.

These are important concerns, especially given the history of paternalism in medicine and the power differential between healthcare professional and patient. And yet, healthcare workers inevitably interact with patients' and families' deepest beliefs, hopes, worries and ways of making meaning. When these deeper values are left unspoken it can lead to misunderstanding and discord that adds to the distress of patients and families going through some of the most difficult moments of their lives, and also to profound moral distress among members of the healthcare team.

Prayer is the most common alternative therapy in the United States, and studies suggest that most patients want their healthcare providers to talk to them about their beliefs and how they impact their medical decisions. A patient's spirituality and/or religion is inextricable from their sense of self and connection to and place within their culture and communities.

When navigating differences in culture and belief, including when a family expresses hope for a miracle it can be helpful to remember a few simple practices, which I think of as instances of "beginner's mind"—ways of approaching the patient, and yourself, with attention, curiosity and kindness:

A religion of one

When we encounter a scenario that touches on our past experience, especially a negative experience, we can be quick to make assumptions. Each religious person shares much with other practitioners of their

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faith, but they also are a “religion of one,” with their own story and context that shape their beliefs and practices in ways that might surprise us. Cultural competency can help us do our jobs more justly and thoughtfully, but no amount of competency obviates the need for cultural humility.

One moment more

We know from the research that patients benefit when their team makes an effort to listen more and talk less. This can look like asking one more question or allowing one more moment of silence.

Just as healing can mean many things within one’s particular cultural, spiritual and emotional context, so too can the word ‘miracle.’ We might ask something like, *“You’ve told me you’re hoping for a miracle. I’m curious, what does that word mean for you right now?”* Often, the miracle they are hoping for is what the team might assume—cure, or the return of organ function, for instance. Other times, the answer might surprise the asker. Regardless, the answer will teach the team more about what is most important to the patient and family, and the question will create an opportunity for the team to join the patient in their hopes, while still clearly conveying medical information. The hope/worry framework employed frequently in Palliative Care settings can be helpful here. We might say something like, *“I will be hoping for a miracle right alongside you, and also I am worried about what the recent scan has showed us. What it says to me is...”*



Noticing what is going on inside you

Just as a patient’s beliefs affect their medical decisions, providers’ own beliefs have been shown to influence how they inform patients about medical options, and how they weigh patients’ expressed preferences, including around end-of-life issues. We all have beliefs that shape our decision making, whether we make them explicit or not. When we have a strong reaction to an experience, or to patient or family member, it can be helpful to pay attention to what is going on for us in that moment, with the same curiosity and kindness we would extend to a patient.

Hospitalizations and illness can disrupt our stories, the way we make sense of the world, and even how we see ourselves. That said, humans are remarkably resilient. It is helpful to remember that the same hopes and beliefs that have supported the patient up to this moment will continue to support them, even when their specific hopes for a miracle are not realized, and if these resources stop working, they will change.

Patients are guests in our hospital, but we are guests in their lives. We see only a snippet of the larger context in which they make sense of the world and themselves. Joining with them in an authentic and curious way in these critical moments allows healthcare workers to respond with integrity and honesty. It also conveys respect for what is most important to the patient. I have seen this done very well when a doctor says something like, *“You know, in the past you told me that when X happened, you would know it was in God’s hands. I am sorry to say I believe we are at that point where there is nothing else medicine can do. You also told me it’s important she doesn’t suffer. Given that, it’s my recommendation that...”* This is an excellent example of a healthcare worker showing



that they have been listening. They are engaging a family on their terms, without needing to share their beliefs. True, this kind of listening and partnering takes time, and despite the best efforts of healthcare workers, there will be cases where the team and the patient will never find common ground. But by approaching the hope for a miracle as an opportunity for curiosity about a family’s hopes, culture and beliefs we can co-create a space of mutuality and respect that will set the best foundation for partnering to make informed medical decisions that are just, kind and equitable.

From the Case Files of the PEC:

Life-sustaining care for an infant with Trisomy 18

Written by: Jane Abbottsmith, YSM 2026

THE CASE

The patient is a 10-month-old female with Trisomy 18, congenital heart disease, and tracheomalacia, currently dependent on a G-tube for nutrition and BiPAP for respiratory support. Prior to this hospitalization, she was clinically stable and not on any respiratory support. Her parents decided to change her status to DNR/DNI out of a wish to spare her the suffering of cardiac resuscitation, but they remain open to further surgical interventions to treat her congenital heart disease, especially if such intervention will improve her pulmonary function. They have expressed the wish that her care not be altered on the basis of her genetic diagnosis, and they hope eventually to bring their daughter home to allow her to grow and flourish in whatever way is meaningful for her. An ethics consult was requested by the care team to determine whether it would be ethically permissible to offer and to place a tracheostomy in this patient.

DISCUSSION

It is important to separate two distinct questions in this case. The first is the question that prompted the consult: at what point do harms to a baby outweigh the benefits of aggressive, life-sustaining treatments? The second is one that might emerge in the course of discussing treatment outcomes: should congenital abnormalities with poor prognoses influence decisions about withholding or withdrawing care? This second question must be teased away from the first in order to avoid confusing the suffering the baby might experience as a result of treatments—pain following surgery, restricted movement from cumbersome breathing equipment, separation from family during important periods of development—and the suffering she might experience as a result of her diagnosis of Trisomy 18—heart conditions, breathing problems, feeding difficulties, developmental delays requiring fulltime caregiving.



The latter sufferings are tragic when they occur and may limit the patient from infancy to adulthood. Nevertheless, a difficult life is not necessarily the same thing as a life not worth living.

It is a subtle but crucial point. We often hear discussion of “quality of life” in decisions about whether to pursue certain treatments, and we should certainly aim to improve patients’ quality of life, all things being equal. Interestingly, healthcare professionals and family members tend to think of quality of life in terms of physical wellbeing, while patients themselves tend to focus more on social and intellectual wellbeing (Hilton et al.). In pediatric ethics, it is important for healthcare professionals and families to consider all dimensions of the child’s wellbeing. But there is a difference between considering the impact on quality of life of individual interventions (whether this or that treatment may help or hinder it) and considering quality of life on the level of the life as a whole (as a standard against which to decide whether or not a life is worth living, or saving, at all). The former can and should be a part of every treatment decision, with the goal of improving the flourishing of each particular child in the face of whatever limitations he or she or may face at this particular moment; but the latter has no place in ethical decision-making and is in grave conflict with respect for each child’s dignity as a human being worthy of value, compassion, and care. In

TRISOMY-18: Continued on page 4.

this case, the family's request that their daughter's care not be altered on the basis of her genetic diagnosis was an expression of such respect for her dignity and worth; in a better world, such a request would not even need to be made.

The question the ethics committee set out to consider, therefore, was a question about a particular life-sustaining treatment—the placement of a tracheostomy—and whether it would help or harm this young child. In the course of the discussion the committee considered a number of competing factors: on the one hand, the hope to help the child survive an episode of respiratory distress; to reduce her hypoxemia and improve her health; to help her return to her home, her family, and the rest of her life—all of which might be helped by, and perhaps might depend on, the life-sustaining intervention of a tracheostomy. On the other hand, the committee recognized the density of developmental milestones during this period of life, the value of freedom of movement, and the importance of interaction with her family both for her and for them—all of which might be hindered by the cumbersome and restricting intervention of a tracheostomy.

The committee's discussion highlights the importance of clarity about goals of care. Is it possible for this child to survive this acute decompensation, making it reasonable to accept



the harms of a tracheostomy in light of the very great goods of health, life, and flourishing at home? Or is it more likely that her decompensation will continue despite the best efforts of her care team, making it more important to shift the focus to minimizing her discomfort, supporting her developmental expression now, and allowing her to have meaningful interactions with her family in her remaining time? These conversations are difficult for family members to have, and families may need help identifying these goals. It is easy for delivery of information from the care team to be fragmented, especially when specialists and consultants are involved, and important to have clear, frequent conversations with families as events unfold.

CASE RESOLUTION

At the time of the ethics consult, in the case of this critically ill child, it was impossible to know whether or not she would be able to survive her acute illness and return to her prior state. The ethics committee recommended that it would be ethically permissible to pursue further life-sustaining interventions, including the placement of a tracheostomy, and also pursue cardiac interventions if a careful analysis of risks and benefits to the child, as well as could be defined, would favor that course. The committee recommended that all of these options be offered to the family.



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Life-sustaining care for an infant with Trisomy 18

The committee agreed, however, that it would also be ethically permissible for the family to decline such interventions, and to support the goal of improving their daughter's life in the short term with the hope of helping her spend meaningful moments in whatever time she had remaining. Such care might mean allowing her less time on BiPAP and increased time on nasal cannula so that she could have mobility, freedom of movement, and the best chance of interacting with her family.

Ultimately, the family decided to forego tracheostomy placement but to continue to pursue further cardiac interventions. Their daughter recovered from her respiratory distress and was able to resume her life at home.

LITERATURE

Hilton T, Orr RD, Perkin RM, Ashwal S. End of life care in Duchenne muscular dystrophy. *Pediatr Neurol* 1993; 9: 165-77.

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.

Trisomy 18

By Kevin Wang, YSM 2022

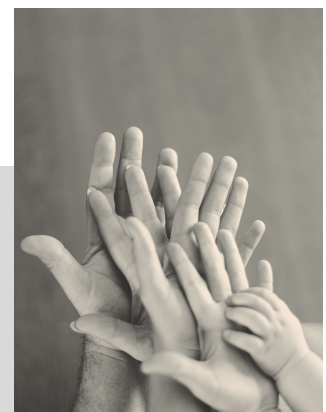
leaning over
your snowy crib,
I attach to you,
angelic skin
Startled
by callous metal.
buds of fingers
clenching shadows,
pearls for eyes
asking me,
where is mother?
she left
to forget.
chhh dub,
chhh dub,
your tiny heart cries.
I hear,
I'm here.

Wang, Kevin. Trisomy 18. *Intima: A Journal of Narrative Medicine*. Spring 2019.

ABOUT THE PEDIATRIC ETHICS 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



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.

Moral distress is a real experience of nurses and others.

DEAR ASCLEPIUS: I am a pediatric nurse, and one of the hardest things I have encountered in my work is being asked to carry out treatment of children when it seems the treatment is causing more harm than good—for instance, participating in aggressive measures that are only prolonging the dying process. I became a nurse because I wanted to care for patients, and in cases like these I feel more like an agent of harm. I am uncomfortable voicing these feelings because I do not want to be seen as challenging team decisions and worry that I will be criticized. Do you have any advice about what to do in cases like these, or how to speak up? --VOICELESS IN THE ICU

DEAR VOICELESS: First of all, thank you for your question. It sounds like the feeling you are describing is moral distress, the emotion felt when being tasked with doing something you believe is morally wrong. In this case, it is compounded by your feeling of being voiceless. Even though the benefit of collaboration amongst care team members has been demonstrated again and again, vestiges of the old “hierarchy” can make nurses feel less valued or respected on the care team.

As a pediatric nurse, you have incredibly important insights into the care of your patients that are crucial for the team to hear and appreciate. YNHH has a policy of openness and mutual respect that means everyone should be able to speak up without fear of reprisal. Is there anyone on the team that you would feel comfortable confiding in? If you could present your feelings together, you might be able to avoid the difficulty of speaking up individually. You could also contact the ethics committee and request a consult anonymously.

In whatever way you choose to do so, I encourage you to make your voice heard. No one should feel forced to participate in actions they believe are morally wrong. Your distress also signals serious concerns about the care of your patient, and your insights are invaluable in guiding treatment decisions. Please continue to cultivate a culture of collaboration at YNHH. And thank you wholeheartedly for the work you do.



PEDIATRIC ETHIC COMMITTEE MEMBERS

The program educates clinicians, staff, residents and medical students on issues related to pediatric ethics, and provide consultation services to patients, families and staff.

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