

Getting to Good: The Ethicist's Role in Critical Care

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I sat down with Bibler in June 2018 to discuss how bioethicists work with patients, families, and the clinical team to facilitate shared decision-making and resolve ethical conflicts in the critical care setting.

To learn more about ethicists in critical care, please read "Setting Expectations for ECMO: Improving Communication Between Clinical Teams and Decision Makers" in this issue of the Methodist DeBakey Cardiovascular Journal.

What is the ethicist's role on the health care team?

TB: We try to assist in good patient care, but more specifically, we're trained to address areas where there might be ethical conflict or ethical confusion. In this context, we define the ethical conflict based on information from the clinician requesting our help. It usually has to do with the language of, "We're not sure if this is the right thing to do" or "I'm really feeling distressed about this decision." We listen for barriers and words like "right and wrong," "good," "too risky," or "futile." When we hear those touchstone words, we then try to link it back to an ethical question, then help with patient care on that path.

What type of cases are you typically involved with?

TB: About 50% of our cases have to do with end-of-life care. We go to interdisciplinary rounds every day in the MICU and the CVICU. If there's one paradigm case that every ethicist needs to be an expert in, it's when you have perceived conflict between a medical care team that thinks continued interventions are inappropriate and a family talk with the medical care



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team. Often they actually agree about where to go, but they're not quite sure how to effectuate that decision and make it real.

However, when there is actual deep-set conflict, then it's usually not just about communication. Then it's about bedrock ethics issues, like real disagreement about what a good death or a good life would look like for the patient. The most common area where this pops up is related to religion. When a patient or their family's religious tradition really prizes an idea of life even if it means not being able to interact, or trying invasive treatment options despite little chance of recovery it's especially difficult to reach consensus. In those situations, where there's fundamental disagreement, even perfect communication won't solve the problem. You can sometimes use mediation strategies and facilitation to try to at least find some shared goals, but sometimes it's just not feasible.

How do you approach a situation where the patient isn't going to recover, but the family is adamant that you continue care?

TB: One method that I've found helpful is time-limited trials. For example, when the medical care team doesn't think that dialysis would be appropriate because of the patient's overall illness, but the family thinks it would be in the patient's best interests, the physicians can say, "We're willing to try it for two weeks, but if we don't see X improvement in that time, then we're going to stop dialysis and allow comfort care." Time-limited trials, as long as you're very specific about what the intervention is, what its goals are, and what the limits are, can be very helpful. However, they fall apart if clinicians aren't clear about what improvement looks like or don't stick to the original plan.

Another practice that I find extremely helpful is reorienting the conversation. Ethicists always try to reorient the conversation around the patient's preferences, goals, wishes, and values because often surrogates are so overwhelmed that they have a hard time distinguishing between what they want and what the patient would have wanted. There the ethicist can ask, "What would the patient be saying to us?" Sometimes that can help break a conceptual log jam.

The other strategy that I use is not having an all-or-nothing approach and instead saying, "Okay, we understand that you want keep fighting, the patient's a fighter. However, we feel a bit uneasy about this for various reasons..." With this mode of nonescalation, we can say, "We understand your concerns, but if the patient gets sicker, we don't think it would be appropriate to restart her heart or to re-intubate" and so on.

Okay, that makes sense. So how do you approach getting a 360° view of what's going on in a patient's life?

TB: When we see the patient in the ICU, we get a very tight snapshot of that patient's life, but with questions that appeal to both the past and to how they envision the future, it helps us get a broader picture of what is important to that patient. A question that I found extremely helpful is, "What did a good day look like before you (or your loved one) got sick?" When you ask that question, the patient or their surrogate is forced to think about how things were going up until this point. Then you can help them think through what a good day would look like in the future. For example, I recently had a case where it was very clear that the patient had a pretty active life. They were engaged in lots of physical activities, independent, super mobile, very intellectually interactive. They really prized both the life of their mind and of their body. So I learned this whole spectrum of what a good day might look like, from helping

around the house to weekly trips to the gardening store. That's where the value was for this patient. However, the clinical team was telling me that the chance of them getting back to that point was nearly zero. So then we needed to think about what life or death might look like moving forward now that we knew that the types of things that they found valuable were off the table.

As the ethicist, I do not give out specific clinical information most of the time, but I'll have these in-depth conversations with families and patients and then arrange for a family meeting where the clinical care team can give a clinical update and make a recommendation. And then I often find myself reframing the recommendation in terms of these daily activities that the patient finds important. I sometimes ask, "How do you think this story's going to end?" or "What would a good ending to his story look like?" I use explicit, narrative-based language to help surrogates think about the future. Of course, that type of question is very, very personal and I would only ask it after the knowing the family or the patient for quite a while. It's easy to offend when you're forcing somebody to think about the possibility of themselves or their loved one no longer existing.

When you're thinking about all the ways that a procedure that might affect someone's life, do you take into account financial considerations and how that could affect the family down the road?

TB: early every time we have a case, we work with social workers and they help us get a sense of what's financially feasible. A lot of our cases involve very complex discharges, and patient finances always play a role. In terms of institutional resources, we always try to be attentive to the fact that sometimes, regarding length of stay, it can be a real financial challenge to the hospital, so the clinical care team at the bedside can sometimes feel a push to discharge. We always try to take that into account while being attentive to the fact that, in America, there's not an easy mechanism that you can appeal to when financial considerations become overwhelming. We often try to think of creative solutions while also being attentive to the parties with finances at stake.

This push to get a patient who seems medically stable out is sometimes a source of moral distress for clinical care team members. Sometimes they say, "We feel like the patient might not be ready," or "We feel as though we're railroading this family and I don't want to do it, but I'm feeling these other institutional pressures." Again, there's the question of what's right to do in this context. We can help the health care team sort through that.

What would you like the clinical care team to know about how they can best work with you?

TB: Get us involved early and be honest with yourself when you feel like there's a moral conundrum. There may be cases when you are not sure if the surrogate is actually speaking for the patient, or perhaps you see kind of that this is going to be a difficult discharge down the road—anytime you get an inkling that you might have to ask yourself whether you're doing the right thing. Sometimes just based on experience or intuition, you can tell that something is going to be ethically difficult, so getting us involved earlier is helpful.

For example, the heart failure team here at Houston Methodist does a good job of getting us involved early for patients who have concerns about whether they're good ventricular assist device or heart transplant candidates. It's particularly helpful to get ethicists involved from the beginning when the team has concerns with compliance or the patient's understanding of their situation or their ability to think through paths moving forward. In the past we wouldn't get involved until it was much later, like after the patient was accepted into the transplant program and is now refusing the procedure, but now we are involved much earlier.

Not every facility is lucky enough to have full-time ethicists on staff. What is your advice for critical care physicians who have a morally complex cases and they have to guide a patient, the family, and the clinical care team through difficult decisions?

TB: The first thing is to be empathetic to what families and patients are going through. I also think it's helpful to define your own idea a poor quality of life or a good quality of life—and what makes life worth fighting for. You can use that at least in the beginning of these conversations. The other is to take the time to get a sense of what the patient found important, what a good life would be for them. Just think of how helpful it would be for a patient or family to have this empathetic person coming in—they're feeling sick, they're not sure what to do, but now there's somebody here who's willing to actively listen for 20 minutes and get a sense of what's important to them and how they might make medical decisions.

You can explicitly ask a patient or family, "How do you think you made your medical decisions?" Some people instantly say, "Numbers, I have to have the numbers." Some people aren't sure. Others will say, "I'm a person who likes stories and concrete events, so the language of 'you'll never garden again' means a lot more than 'there's a 15% chance of meaningful recovery.'" Those are huge differences in ways of displaying the information.

You can also ask, "What helped you make the best medical decisions in the past?" or "Who should we definitely involve at all times?" Listen for answers to figure out how to work with the surrogate or the patient, but always keep in mind that you have to link up what is medically feasible and medically reasonable with that story.

Ultimately, if you honestly don't think that this patient is going to get back to their version of a "good day," you can use that language and explicitly say, "We don't think you're going to get back to that life and therefore we recommend comfort care," or "therefore we recommend long-term acute care placement."

I think it's helpful to remember that there's a historical, professional, and ethical-legal consensus that medical professionals can make recommendations. Caring for patients isn't just about just telling your patient, "Here are the four feasible options. Which one do you want? Take it from here." It's about hearing what's important to them, considering whether there are interventions that might get back to that, and making those recommendations. If there aren't any interventions that can get the patient back to that mode of living, it's important to be very explicit about what the other path is, what hospice care might look like, what in-patient care might look like. We need to be as clear as possible because we always want to make sure that patients have an understanding of what they're saying yes or no to.

Conflict of Interest Disclosure

Laura Gerik is assistant managing editor at the *Methodist DeBakey Cardiovascular Journal*.

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