VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Receiving Clinical Ethics Consultation Services:

A Teaching Guide for Clinical Ethicists

By Taylor Abboushi

Edited by Heidi A. Walsh

The stories referenced in this study guide can be downloaded for free. Please see the "Receiving Clinical Ethics Consultation Services" volume of VOICES https://nibjournal.org/voices/

Art Frank has written a short reflection piece on learning from narratives for NIB. Please see the Narratives Page under the Education tab on the NIB website to download the piece.

General Questions:

General Questions:

1. Several stories mention barriers to initiating an ethics consultation—both from the point of view of the clinician and a patient's family. What changes do you think could be made to remove these barriers? Whose responsibility is it to make sure ethics consultations are accessible to all who could benefit from them? Does change need to be initiated from the CEC, hospital administration, or another group entirely?
2. A goal of an ethics consult is to arrive at the next steps about a particular case and set of circumstances, but from the authors, it is clear that the process of going through an ethics consultation can have an impact beyond one specific case. When you facilitate an ethics consult, particularly for healthcare professionals, is it appropriate to try and reinforce longer-lasting learnings that teams can apply to future cases? Why or why not?
3. To what degree do you incorporate ethical principles into your thinking or facilitation of a case? How do these principles bring value to clinical ethics consultations? What do you think is the most valuable skill set for a clinical ethicist to have?
4. Should the role of the clinical ethicist (or one of the goals of the CEC) be to prevent moral distress on behalf of the healthcare team? Why or why not? Do you feel it's part of your job now when you engage in consults? As a clinical ethicist, when have you experienced moral distress?
5. How does working as a clinical ethicist change how you communicate with healthcare professionals about either your own care or the care of a family member or other close person? How do you think about things differently now versus when you first started this work?

Story Questions:

Against Their Wishes: The Gift of a Goodbye

Austin Morris

1. Morris recounts positive experiences working with clinical ethicists, both in his time in medical school and in the case of the 25-year-old man he writes about in this story. In your experience, how do most healthcare professionals respond to your involvement in a case? Are you generally met with positivity, neutrality, or distrust?
2. Morris writes that the clinical ethicist in this case "stepped in and served as a liaison between us as medical providers and the patient's family as surrogate decision-makers" and that the ethicist "helped to navigate and bridge the disconnect between our current plan of care and what our next steps should be." Why do you think an ethicist is needed to help communication between healthcare professionals and families? What skills do ethicists have that make them better equipped to do this than other healthcare team members?

Story Questions:

Lisa's Story

Lisa P. (wife of patient) & Jeanne Kerwin

1. Lisa P. contrasts the doctor's and ethicist's responses to her husband's desire to deactivate his left ventricular assist device (LVAD). Where the physician objects to deactivating the LVAD and tells him "no," the ethicist listens to Lisa's husband and reaffirms his right to make decisions. Lisa writes that at the time, she didn't know the ethicist's personal opinion, whereas the physician's was clear. Describe a time when you found maintaining impartiality in a case difficult. What made the case particularly challenging for you?
2. Lisa P. writes that she stayed in touch with the clinical ethicist long after the consultation was complete. Have you found that patients, families, or healthcare professionals want to keep you involved in cases after a resolution has been found? Do you think this is beneficial? How do you manage cases such as this?

Story Questions:

Unbefriended

Jean Watson

1. Watson writes about acting as a surrogate decision-maker for a man who is unconscious at the hospital after suffering a stroke and for whom the hospital is unable to find any friends or individuals to help guide the clinicians on what he might want to be done. What is it like to make decisions for someone whom you don't intimately know or haven't even had the chance to speak with? What information do you consider? If you've never acted as a surrogate decision-maker, what do you think you would consider when making your decision?

2. Watson explains that this ethics consultation took place in Minneapolis, Minnesota, in early June 2020, during the pandemic and at a hospital very close to where George Floyd, an African-American man, was murdered during an arrest days earlier by a white police officer. Watson writes that the "confluence of crises was overwhelming." To what degree should outside current events factor into clinical ethics consultations and decision-making? Undoubtedly, some changes in the law, which must be upheld, limit the recommendations an ethicist can make—does this lessen the value of a CEC if you are limited in this way?

Story Questions:

The Clinical Ethics Consult: Transforming Ambivalence to Action

Eve Makoff

1. The ethicist, Dr. F, says that he and others are able to do this sort of work "because there's no bullshit in this room. It's the only place where there's no bullshit." As a clinical ethicist, what does this mean to you? Do you agree? What helps you to handle the day-to-day work that you do?
2. Makoff writes that, in this case, the family needed help making decisions about the next steps and getting "unstuck." How do you help families or individuals around a patient move forward in their decision-making? What have you learned that helps individuals get "unstuck"?

Story Questions:

Side Stepping the Issues: Disappointment with an Ethics Consult For A Medically High-Risk Patient

Brent R. Carr

1. Carr describes an ethics consult regarding whether to proceed with ECT for a patient and writes, "The ethics consult seemed…relegated as though it were a solitary lab order that had returned a simple, concrete value. And that was the end of the discussion and concerns." In your experience, how do you prevent a "decision" in an ethics consult from being like this—a "simple, concrete value"? Have you found that many healthcare professionals and families are looking for a straightforward *yes* or *no*? Is there pressure in your role to simplify consultations in this way?
2. Typically, do you find that healthcare professionals are interested in engaging in philosophical or ethical discussions? How do you encourage this type of conversation and why do you think some healthcare professionals want to avoid it?

Story Questions:

My Father Dies Alone

Anonymous One

1. The author is unable to request an ethics consultation for his father because the only way he can request a consultation is through Dr. Stewart, whom the ethics consultation is about. This story highlights a clear barrier to patients and their families getting access to a consult. How do you

think the hospital could have prevented this from happening? What could have been done so that the author was able to access a consult for his father?
2. Describe a time when a clinician you were working with "had trouble seeing when their judgments… moved beyond pure medicine and into the realm of ethics." Describe a time when you've witnessed a similar scenario. In your experience, do healthcare professionals, patients, and families seem to have a good understanding of when to involve a CEC? What kind of education or outreach could be done to improve their understanding?

Story Questions:

Whose Voice Matters? The Role of Ethics Consultation in Supporting the 16-Year-Old Healthcare Decision-Maker of a Critically Ill Neonate

Michelle Prong

1. Prong writes about a case with complex family dynamics. The patient—a newborn admitted to the NICU with Trisomy 13—was born to a 16-year-old unemancipated minor. The teenager is the patient's mother and primary decision maker, though the grandmother is heavily involved in making decisions. Describe a case where you had to manage a particularly challenging family situation with multiple decision-makers. How did you approach this case? Does more involvement from a family typically make a case easier or more difficult for you?
2. What is it like dealing with team turnover during a consultation for a patient who is there for a long-term stay? Does it make the consultation more challenging?

Story Questions:

The Healing Power of an Ethics Consult

Laura J. Hoeksema

1. Hoeksema writes that she's "struck by the healing power of an ethics consultation and its long-lasting positive effect." In your experience, is the "healing power" of the ethics consultation in the arrival of a decision, or is it in the process of arriving at that decision (for example, the conversations and the space to have those conversations)? Why do you think this is the case?
2. How do you bring people together to make decisions and perhaps arrive at a place of compromise when individuals, as Hoeksema writes, come with different values and perspectives? Has this process gotten easier for you throughout your time as an ethics consultant? Why, or why not?

Story Questions:

Clinical Ethicists: Can They Help Their Families in Their Times of Need?

Tracy R. Wilson

1. As the medical expert in her family, Wilson felt the medical team was not listening to her family when a close family member was admitted to the hospital with a critical case of COVID-19. Wilson felt that an ethics consult could have been helpful, but unfortunately, their family was never given the opportunity to participate in one. From your own experiences and insight, do you

think clinical ethicists should be proactively included in a patient's healthcare team? Why or why not? Where you practice as a clinical ethicist, what would facilitate CECs being involved in more cases? What are the barriers to CECs being involved in more cases?

2. Wilson relays that aside from the experience with her family member who succumbed to COVID-19, she did not receive any help from a clinical ethicist when her father died, either. Wilson writes that the "clinical ethicist can help the patient and family navigate the healthcare system more seamlessly." Should this be the role of the clinical ethicist? Why or why not?

Story Questions:

"It's All Personal"

Frances Rieth Maynard

1. Maynard and her husband asked for their newborn daughter's ventilator to be withdrawn, given the enormity of her medical issues. Maynard was advised that an unidentified nurse had called an ethics consultant, which made her sad, angry, and scared that a stranger might decide the fate of her daughter. "I felt as though my intentions were suspect, and my own sense of vulnerability became overwhelming." How could news about the ethics consultant have been delivered in a way that would not have been as damaging to the relationship between Maynard and the healthcare team?
2. Twenty-five years later, Maynard now facilitates ethics consultations as a healthcare provider. Because of her personal experience, Maynard writes that she "always tries to keep in mind the 'us vs. them' feeling that she had when she was the focus of an ethics consultation and not the facilitator of one." How can healthcare teams—including CECs—circumvent the "us vs. them" feelings that Maynard experienced?

Story Questions:

Fault Lines

Laura A. Katers

1. Katers writes about Shawn—a 32-year-old man diagnosed with multiple debilitating and painful illnesses that have led him to be frequently admitted to the hospital. On one such admission, Shawn requests to be discharged and put on hospice, though his conditions are treatable (albeit not curable). An ethics consultation is called. For the first time, Katers "saw ethics as an avenue to advocate for those with challenging or misunderstood behavior to have a louder voice in their care and have a seat at their own table." What does this mean to you? How does advocacy (if at all) factor into how you facilitate ethics consultations? How do you know "who" to advocate for?
2. Katers describes getting a chance to share a conversation with Shawn, and she writes, "he is shocked at how his suffering and life feel reduced to rules and checkboxes that are disconnected from what he believes he deserves" and that he feels more "like a villain than a victim of a terrible disease." How do you ensure that an ethics consultation doesn't make the patient feel like they are on "trial"? How do you ensure that those involved in the consultation who may have a differing view from the majority don't feel like the "villain" of the case?

Story Questions:

Difficult, Difficult, Lemon, Difficult

Maggie Taylor

1. Taylor's husband "is a lemon—he suffers from manufacturing defects that prevent his body from functioning as intended." In her story, Taylor shares that her husband is admitted to the ICU and intubated after suffering from an epileptic seizure that led to aspiration pneumonia. Having discussed various medical interventions with her husband previously, Taylor relays to the physician that her husband would want to be extubated. Ultimately, the physician calls an ethics consult, which Taylor describes as "an act of theater" since her husband, by then, lacked decision-making capacity. Have you ever been in a consult that felt like an act of theater? What do you think the clinical ethicists could have done differently in Taylor's husband's case?
2. Taylor's husband was transferred to a different hospital, extubated, and made a full recovery. Reflecting on the situation, she asks, "Was the consult successful?" After reading Taylor's story, what do you think? What generally makes a consult a "success"?