



# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

## Receiving Clinical Ethics Consultation Services





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## Introduction

# Receiving Clinical Ethics Consultation Services

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**Abstract.** This symposium includes twelve personal narratives from those who have received clinical ethics consultation (CEC) services as a healthcare provider, patient, family member, or patient advocate. Three commentaries on these narratives are also included, authored by experts and scholars in bioethics, healthcare ethics consultation and certification, narrative medicine, and policy. The goal of this symposium is to call attention to the experiences of people who have received clinical ethics consultation (CEC) services as a healthcare provider, patient, family member, or patient advocate.

**Key Words.** Ethics Consultation, Patient Advocacy, Health Personnel, Delivery of Healthcare, Medical Ethics, Narratives

## Introduction

The past several decades have seen a substantial rise in prominence of two phenomena once secondary to clinical decision making: 1.) the financial dimensions of healthcare and 2.) the increased role of the patient's voice in clinical decision making. Both have been influenced by the emphasis on evidence-based medicine, both in determining how healthcare might become more affordable and cost-effective, and (relatedly) in the emphasis on documenting value and appropriateness of treatment and care plans and strategies. Clinical Ethics Consultation (hereafter, CEC) has

been influenced by both the rise in prominence of financial considerations as well as (and especially) patient rights. Past controversies concerning how to allocate limited resources like kidney dialysis machines (Jonsen, 2007) and the role of patient values in determining under what circumstances artificial life support is and is not appropriate (Aulisio, 2016) gave rise to hospital ethics committees and eventually hospital-based ethics consultation services, now widely available in tertiary care centers. (Fox et al., 2022)

As guest editors, we represent both the clinical and educational aspects of clinical ethics. Dr. Craig is the Director of a regional ethics department in a



large healthcare system; and Dr. May leads bioethics education and research at a medical school that offers a Graduate Certificate in Medical Ethics aimed at hospital ethics committee members. Together, we have extensive experience working with ethics committee members, as well as confronting challenges faced while training practicing healthcare professionals for this role. We also have first-hand experience with the challenges faced in providing evidence-based data to evaluate the value and effectiveness of ethics consultation services and individual ethics consultants.

Traditional metrics for measuring the value of various hospital services all have fatal flaws that undermine the appropriateness of their application to ethics consultation. For example, satisfaction scores (from both patient families and the healthcare team) are tempting because, in practice, ethics consultation will very often increase comfort with difficult decisions and improve satisfaction among all parties involved. However, in some circumstances, this will not be the case, and these can represent profoundly important cases at the heart of the mission of ethics consultation. Some years ago (Craig & May, 2006), we described this flaw for evaluating EC through traditional satisfaction scores using the example of a case that involved a patient with severe cognitive disabilities, who nonetheless lived a very happy and otherwise healthy life (with support and supervision). This patient was in the ICU with an acute condition that required temporary life support, but was expected to recover to baseline. Despite this expected recovery, both the attending physician and family agreed that life support should be withdrawn: for the physician, due to a belief that the patient's baseline quality of life was sufficiently poor as not to merit the expenditures required to return the patient to baseline, and for the family due to a not—quite recognized as such—weariness from carrying the burden of support and supervision of this now middle-aged patient. An ethics consultation requested by the patient's nurse concluded (correctly, we believe) that withdrawal of life support for these reasons would violate the patient's basic human rights and be contrary to the patient's wishes for recovery. To introduce a potential conflict of interest

for the ethics consultant between advocacy of this patient's rights and the negative effects of the likely poor satisfaction scores that would result from a recommendation at odds with the desires of the individuals most likely to be surveyed is to introduce a conflict of interest that potentially undermines the very heart of this service.

Similarly, traditional cost-related metrics (such as reduced length of stay) also pose potential conflicts of interest. Knowing that the value and effectiveness of EC is (at least partly) measured in these terms can subtly influence recommendations toward outcomes such as earlier withdrawal of care, refusal of costly aggressive interventions, or discharge from the hospital, independent of the advisability of these outcomes in a particular case. These outcomes are very often appropriate and can indeed be facilitated earlier through ethics intervention in many cases where earlier resolution *is beneficial to the patient* (and more consistent with the patient's rights, such as when family is hesitant to follow a patient's clearly applicable advance directive). However, the potential conflict of interest that might bias the ethics consultant toward the outcome also affects other cases at the heart of the ethics consultant's purpose and role, just as it does in the case described in the previous paragraph.

Attempts to measure cost-effectiveness in non-traditional terms, such as appeal to cost savings like reduced malpractice litigation, are also tempting, given studies that demonstrate the effects of open communication on the propensity to litigate (May & Aulisio, 2001). However, these can also prove problematic. This is so for several reasons: 1.) hospital legal departments are (understandably) reticent to share litigation data and details, 2.) even where this becomes available, the attempt to demonstrate value through counter-factual hypothetical evidence (e.g., this litigation was avoided because of the intervention of EC; or this litigation would have been avoided if EC had been requested) are based on probabilities, and 3.) speculation for any particular case makes such metrics inherently difficult to quantify.

To be certain, the field has been working on ways to modify and combine these various factors into more useful metrics (Crico et al., 2021;

Guidry-Grimes et al., 2019). But it remains true that accurate metrics continue to be elusive, leaving the field in the vulnerable position of needing to demonstrate tangible benefit while lacking an acceptable, measurable standard.

Given these challenges, it is our belief that the value of ethics consultation is likely best captured through narrative. The stories of actual parties who experience ethics consultation can provide insight into the varied ways in which a case might be affected by EC, the types of assistance EC offers to clinical decision making, and the effectiveness of EC in any particular unique case. With this belief in mind, we were motivated to sponsor this special issue of *Narrative Inquiry in Bioethics* with hopes of advancing recognition of EC's value in the hospital setting and considering the limitations of traditional metrics for capturing this value.

### The Call for Stories

The call for stories sought to hear from those who have received clinical ethics consultation (CEC) services as a healthcare provider, patient, family member, or patient advocate. Authors were asked to consider the following questions:

- What do you see as the primary role of the CEC service? How well did your consultant fulfill this role?
- Did the CEC assist you in making care decisions?
- Did the clinical ethicist value your perspective as a participant in the consultation? If so, how? If not, how did that make you feel?
- Was there anything surprising about the CEC? Is there anything you think others should know before requesting a consult?
- What did you find helpful about the CEC? What was not helpful? Based on your experience, would you recommend the service to others? Why or why not?
- For patients, families, or surrogate decision-makers: how did the consult affect your relationship with the healthcare team and/or your family? Do you think the CEC contributed to doing what was best for the patient?
- For healthcare workers: how has your engagement with a CEC influenced your practice? What would you like hospital leaders and decision-makers to know about your experience with a CEC?

The editors of *Narrative Inquiry in Bioethics* published the call for stories in the *NIB* newsletter and on the *NIB* website. Additionally, the call was posted on several social media platforms, including LinkedIn, Facebook, and X (formerly Twitter). It was distributed through the American Society for Bioethics (ASBH), the Clinical Ethics Consultation Affinity Groups (CECAG), and the Medical College of Wisconsin (MCW) listservs. The editors shared the call through the Washington State University bioethics grand rounds announcements, all regions of Kaiser Permanente, the University of California, San Francisco (UCSF), and Sutter Health. The Canadian Bioethics Society shared it with its members. It was also shared with and by many of our colleagues and experts in medicine, clinical ethics, and patient advocacy.

### The Narratives

The stories in this issue are remarkable in their illustration of the myriad parties who might benefit from ethics consultation. From physicians to families (i.e., parents of adult children, as well as spouses), nurse practitioners, and indeed the gambit of multidisciplinary teams (as illustrated in the story describing how the ethics service facilitated the development of an effectively collaborative interdisciplinary team), these stories illustrate the wide-ranging “audiences” who can and do benefit by the presence of ethics consultation services.

Consistent with the challenges of developing standardized metrics for evaluating ethics consultation, the value added by ethics varied widely in the cases described. Indeed, the task of ethics itself varied in the cases described. Some authors wrote about the CEC helping to clarify and translate a patient's values to treatment goals. In other narratives, authors described the CEC assisting the healthcare team in understanding and becoming more comfortable with decisions. Some CECs in the stories provided empathy and support for difficult decisions—it is not easy to allow a loved one to die, no matter how clearly you know that is what aligns with their values and wishes. Other CECs clarified the role of one's own values when acting as a surrogate for another (as one ethicist did for an

informal committee of surrogates for a patient with no identified friends or family). The narratives highlight that CECs deal with unavoidable uncertainty. The task of ethics is as wide as the applicability of normative values themselves.

The consultations described demonstrate the value of honesty, logic, and analysis, and straight-forwardly facing the need to grapple with undesired circumstances and uncomfortable discussions. Perhaps most importantly, they describe a need for ethics services to help give voice to patient values and opinions (and, as described in the story of a bioethicist in the role as a family member, the need for ready accessibility in order to fulfill this role). They also illustrate the value of familiarity with the often-disconnected worlds of moral reasoning and clinical “trenches,” a dual familiarity that requires both a practical mindset and theoretical ethics training that bridges both world perspectives and emphasizes the value of both ethical and clinical training for the conduct of this important service.

## The Commentaries

This symposium also includes three expert commentaries on the narratives. The commentary authors—Arthur W. Frank, Felicia G. Cohn, and Ruchika Mishra—provide unique perspectives informed and enriched by their expertise in medicine, bioethics, education of healthcare professionals, health policy, and improving healthcare for vulnerable populations.

Arthur W. Frank is a professor emeritus of sociology at the University of Calgary. He has been a visiting professor at several universities, most recently VID Specialized University in Oslo, the Program in Narrative Medicine, Columbia University, and the University of Ghent. Dr. Frank is the author of “At the Will of the Body” and “The Wounded Storyteller,” among other books on illness experience, ethics, and narrative. His most recent book is “King Lear: Shakespeare’s Dark Consolations”. Among his awards are the Royal Society of Canada’s Medal in Bioethics and the Canadian Bioethics Society’s Lifetime Achievement Award.

Felicia Cohn is the Bioethics Director for Kaiser Permanente, Orange County, where she provides clinical ethics consultation. She is also a Clinical Professor of Bioethics in the Department of Medicine at the University of California, Irvine School of Medicine, where she previously chaired the Ethics Committee. She formerly served as President of the American Society for Bioethics and Humanities and was the inaugural chair of the Health Care Ethics Consultation Certification Commission.

Ruchika Mishra is the Bioethics Program Director at Sutter Health in Northern California. She has over 15 years of experience in Clinical Ethics and is involved with consultation, education, and policy. She is also an elected member of the ASBH Board of Directors. Dr. Mishra served as an Associate Editor on the 9th edition of Jonsen, Siegler, and Winslade’s “Clinical Ethics.” She has contributed to multiple journals and scholarly activities in bioethics.

## Conclusion

Ensuring the provision of quality ethics services in healthcare will require that value be demonstrated and that educational programs reflect the value added by hospital-based ethics services. We hope that the stories collected herein will help communicate the difficult-to-measure value of ethics services, as well as inform training programs aimed at preparing those charged with providing ethics services in the clinical setting for this important role.

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## Personal Narratives

### Against Their Wishes: The Gift of a Goodbye

Austin Morris

Think back, if you can, to when you were once a 25-year-old young adult. Think back to your hopes, your dreams, your overall plan and expectations for life and where you think you would end up one day. Now imagine facing your own mortality; life as you have known rapidly approaching an end that you were not able to prepare for prior to its arrival. Imagine the fear, the uncertainty; imagine how your family and friends would feel surrounding you on your deathbed.

The above was the reality for one of my patients. He was a 25-year-old gentleman rapidly approaching the end of his life. As a physician, it is our duty to do no harm and provide the best standard of care to each patient we see on a day-to-day basis. In some cases, what truly constitutes the best standard of care is uncertain, and oftentimes, we find ourselves stepping out of medicine and into the world of medical ethics. Upon arrival to the hospital, this patient's initial decision was to be made full "Do Not Resuscitate" and "Do Not Intubate." This decision was made while the patient was suffering mild

symptoms of alcohol withdrawal. He was evaluated by psychiatry, we reviewed every medical note we had to assess for signs of depression, and ultimately he was deemed competent, demonstrating a mental capacity to understand his current healthcare status and the ramifications of the decision he was making.

As a 28-year-old resident physician, my experience with medicine may be limited relative to those surrounding me in the profession. My intuition, though, has been sharpened with numerous experiences over the last two years dealing with patients driven into depression following the COVID pandemic, finding solace in the use of hard liquor, and subsequently suffering the side-effects of its toxicity. This 25-year-old patient, upon initial assessment, appeared closer to the age of 40; his eyes were icteric, his skin was profoundly jaundiced, and his abdomen distended visibly underneath his hospital gown and blanket. His mother sat at his bedside, fully unaware of the severity of his condition. The patient was angry, questioning why he was admitted and shouting at his mom for forcing him to be evaluated. My initial review of his chart was as in-depth as it could be for having such a limited health history available. Despite that, I could see the path that this would head down over the next 48 hours. Withdrawal was inevitable. The likelihood of needing intubation within the next 24 hours was extremely high. The only bit of uncertainty I was left with was whether or not this patient would survive following these anticipated life-saving interventions. I had anticipated that this would be a long, tenuous, and challenging admission requiring the highest level of care both for myself as a physician and through the healthcare system within our hospital as a whole. But what I did not anticipate was discussing whether or not a 25-year-old should be a DNR/DNI patient.

By day 2 of the patient's admission, evaluation by hepatology confirmed my suspicions; this patient was suffering from fulminant liver failure, and without a transplant, he would surely die. However, we were not able to have this discussion with the patient, as his withdrawal had progressed to the point of disorientation and agitation. The brief episodes of consciousness were spaced through long

periods of unresponsiveness. Prior to this, as mentioned above, the patient was alert and oriented x3 and had expressed, in no uncertain terms, a DNR/DNI status; the confounding factor, though, was during his time awake, he had not been evaluated by hepatology and had not been diagnosed with fulminant liver failure. As such, the prospect of a liver transplant, which would provide life-saving treatment and potentially a path back to life as this patient knew it, had not existed then. Knowing that my time was limited before the patient would fail to protect his airway and would inevitably die, I reached back out to the patient's mother to discuss one last time the prospect of his code status and whether or not he would have wanted to pursue the liver transplant, should it be available to him. This immediately raised questions about the overall ethical implications of discussing code status with a patient's next of kin despite their previously expressed wishes. My co-residents, attending physician, and I were all aware of the implications this decision would hold, and at that time, we knew that an urgent ethics consult was needed to help guide us. During this conversation, the patient's mother stated that the patient would in fact want to be intubated and provided with life-saving measures in the event that a transplant would save his life. She felt that because he was not aware of this option prior to his inability to further participate in a conversation, he would have changed his mind and sought all interventions.

During my time as a medical student, I had the pleasure of working with a clinical ethical consultant throughout my four years; honestly, looking back, I feel it was one of the most enjoyable experiences in medical school. Realizing that the role they play in medicine is often not well elucidated and frequently goes unrecognized, I cannot overstate how much their guidance in this case was appreciated by myself and my team.

When we reached out to the ethicist, we not only had a phone call within 15 minutes of the consult, but we also had direct communication with the ethicist and the patient's mother serving as next of kin. Navigation of this conversation would not have been possible without the expertise provided by our

ethicist; the implications and ramifications of overriding a patient's clearly stated desires would only be appropriate with the sound and just interpretation of the facts overlying this case. Despite all of the information, the legal aspects, and the patient's critical health status, our ethicist guided our team and the patient's mother to achieving the decision regarding the patient's plan of care in under 30 minutes. While I understand that haste may not be appropriate for some ethical cases, time was of the utmost importance to us as the patient was rapidly deteriorating and approaching the need for life-saving interventions.

As much as I wish I could say this patient ultimately was able to undergo hepatology evaluation and subsequently receive a liver transplant to achieve full recovery, I must admit that the ending is much more tragic. By the fourth day of this patient's admission, he was deemed not a candidate for liver transplant by the hepatology team secondary to his ongoing alcohol use prior to admission and his lack of social support. This is where the need for ethics would essentially end for most patients. We decided to intubate the patient. He would not receive a potentially life-saving liver transplant, and we would continue our current plan of care until he would inevitably suffer complications associated with liver failure and eventually pass away.

However, if you can recall, this patient was made only full code on the basis that a life-saving liver transplant would be made available to him, otherwise, through discussions with the patient's mother, the patient prior to his falling unconscious, and psychiatry in our hospital, the patient was appropriately identified as a "Do Not Resuscitate" and "Do Not Intubate" patient. Once again, we began the process of rediscussing the need for code status conversations with the patient's family. We found ourselves asking, should the patient have all life-saving measures discontinued at this point? Given his previously discussed wishes, do intubation, vasopressor use, and any other invasive measures have any standing in this patient's continued care?

This is where our clinical ethicist once again stepped in and served as a liaison between us as medical providers and the patient's family as



surrogate decision-makers. Factoring in every available variable, and considering every piece of information—both in this case and in prior legal cases—our ethicist helped to navigate and bridge the disconnect between our current plan of care and what our next steps should be. After a long discussion, the decision was made to continue care as the patient’s mother began to discuss more about the patient’s battle with depression, his alcohol abuse, and his grandmother’s experience with healthcare and transplant difficulties shaping his views on healthcare. The patient’s full code status was maintained, and he continued to receive life-prolonging interventions.

I will admit that the final decision to keep the patient full code, despite all of the discussions we had had prior to his need for intubation, was not easy for me to accept. Understanding every case is unique, and analyzing factors pertinent to each patient allows us as medical providers to personalize the outcomes for each individual we see. I acknowledge that this patient was 25 years old, there were underlying concerns for depression, and one could argue that between the alcohol use and the patient’s age that their overall mental capacity and reasoning may never have fully developed. The decision to override his wishes sat in my conscience every single day; they haunted me as I returned to work each day seeing him, knowing he was still intubated. This remained true until about day 15 of his admission; the intensive care team had made enough headway in his care to extubate the patient. I walked into the room shortly after he had become fully conscious and it was the first time in two weeks, I was able to hold a conversation with this patient. I will never forget, as I sat down and talked with him, when he told me thank you. I asked him what he was thanking me for, and he took a second, and he said for choosing to intubate me. Given his ongoing confusion secondary to his recent extubation and his liver failure, he was not able to articulate things in the best way. However, our conversation continued to circle back to the fact that if nothing else, he was given an opportunity to talk to his family again, tell them he loved them, and share all the stories of his life.

Unfortunately, this patient would suffer numerous complications during his admission, require multiple intubations, suffer multiple cardiac arrests, and would ultimately succumb to his disease. Despite this, I will forever look back on that case with the memory that this patient was given another opportunity to tell their family they love them, an opportunity and experience that both the patient and his family never would have had before. But, truth be told, none of this would have been possible without the guidance provided by my ethicist. I believe he should have been the one in the room receiving the gratitude from the patient. I genuinely wish I could name this ethicist, because their hard work and expertise in this situation gave me one of the most memorable experiences of my medical career.



### **Lisa’s Story**

Lisa P. (wife of patient) & Jeanne Kerwin

**M**y husband suffered from sudden onset of heart failure with a very low ejection fraction and was on IV Milrinone at the age of 47. One of the most powerful things he told me was that he was not afraid to die and therefore did not want to move forward with Milrinone. He eventually “did it for the kids.” After the Milrinone drip was no longer working, he was offered an LVAD (left ventricular assist device) to keep him alive. He refused, but the doctor again convinced him to “do it for your kids” and said, “we put these devices in 80-year-olds.” He did not have time to explore any other options and reluctantly accepted the LVAD. It was implanted in May of 2014 in a very long and complicated surgery with a long and difficult recovery. He was in the hospital for a long time, and then he refused to go to rehab upon discharge, making it difficult for our family to manage, as he was extremely weak and needed care of his wound dressing. He worried about the financial

impact of a heart transplant and the medications required, as we were already struggling with the medical bills. He refused to have more surgery with the potential complications and never agreed to get on the transplant waiting list.

After the implanted LVAD, my husband was not able to do most of what he loved in life. He couldn't work (he was a truck driver), he couldn't go fishing or swimming in the ocean, he couldn't go hunting and fishing, and his overall physical condition was so poor that he couldn't cook, garden and, most aggravating to him, he could not take a regular hot shower. The LVAD had to be covered with plastic in order to avoid getting the drive-line area wet, so bathing was a complicated process. He had trouble with stairs, had neuropathic pain in his legs from diabetes, and because of the pain medications, he felt cloudy and dizzy and slept most of the day in his recliner. I took care of him, even after I had to go back to work, and at the same time, I managed our two children (ages 9 and 12 at the time of LVAD).

After almost two years of living with the LVAD, multiple hospitalizations for GI bleeds then seizures, more medications, and weekly blood draws for INR<sup>1</sup>, my husband requested that the LVAD be de-activated and that he be allowed to die of his heart failure. He described his life as "miserable." He watched as his misery impacted his children and me. He suffered daily and had none of the joys that made life worth living for him. When we approached the cardiac team that implanted and monitored his LVAD with his request, they said "no." They would not de-activate the LVAD because it was working. It was keeping him alive and he had no other terminal illness. His palliative doctor, who was treating his pain, also heard his request and told us to call for an "ethics consult" to determine if he would be "allowed" to have the LVAD de-activated. We got the number and called on March 31, 2016.

At the time of the call to Ethics, we had no idea what "Ethics" was, other than a general definition

of the word ethics as in professional behaviors and such. We did not know what to expect but we called. We would never have known to call "Ethics" if the palliative doctor had not advised us to do so, and my husband might have suffered a longer, more painful life both mentally and physically prolonged by the LVAD.

We explained the request to the ethics consultant. She listened to my husband describe his daily living and his dissatisfaction with the quality of his life, his physical and emotional suffering, and his wish to rid himself of the LVAD and allow nature to take its course. There was actually no decision to be made on his part. He had already made up his mind. He just needed permission. He wanted to get out of the hell he was living in, which was the result of living day-to-day with an LVAD.

The consultant listened and helped us look at the many sides of his decision. She almost, in a sense, protected our opinions and beliefs on this decision, even though the doctors were very adamant that he should not do this and that he *could not even* do this. She advised us that every patient has a "right" to refuse artificial life-supporting interventions. She told us she would speak with the cardiac team of doctors for more information, and we would set up a full "ethics consultation" meeting for the following week.

The meeting was held on April 6, 2016. My husband and I were there, the ethics consultant with another member of the ethics team who was a physician, as well as the chaplain for the ethics team. The consultant had spoken with the cardiac team and understood my husband's medical history and current status. I felt the ethics consultant really understood where my husband was coming from. I do not know what her personal opinion was at the time or whether she was being pressured by the cardiac team to disagree with my husband's request. However, she put my husband at ease and made him feel that he was being listened to and not given a hard "no." Nothing surprised me about the ethics consult because we had no expectations or knowledge about ethics consultations before we met. We were relieved that someone was listening to my husband's wish and his rationale to be rid of the LVAD.

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<sup>1</sup> *International Normalized Ratio (INR) is a measure physicians use to determine the time it takes for blood to clot.*

The resolution is foggy in my mind because it was such a difficult time. The consultant was concerned about our children and referred us to a children's bereavement service. She also negotiated (or came to a compromise) with the cardiac team. They felt that more could be done to improve my husband's quality of life. My husband then agreed to a 3-4 month trial of going to a psychiatrist for his depression (even though he was already taking antidepressants) and seeing a pain doctor to improve his leg pain. The cardiac team reluctantly agreed that he could de-activate the LVAD after this trial period if the psychiatrist agreed that he had the mental ability to make this decision and that his pain doctor had maximized the efforts to control his discomfort and pain.

My husband stayed with the "trial period" for about nine months, during which time we worked with the kids to help them understand what might happen and why. He was still adamant that he wanted the device de-activated. However, because he now knew that it was possible for him to have it de-activated, he was not as anxious. In the meantime, my husband's physical condition continued to decline, as did his quality of life, in his view.

Another ethics consultation meeting was scheduled on January 30, 2017, to hear from us whether my husband still wanted de-activation of the LVAD and if the family was supporting that wish. The ethics consultant, the ethics chaplain, my husband, my husband's sister, and I were all present. The purpose was to re-visit my husband's request and to see if anything had changed or if there were other reasons not to move forward. The ethics consultant determined that my husband had complied with the trial period requirements and that he continued to describe his reasons for wanting de-activation of the LVAD to allow his death from his underlying heart failure. She assured us that she would meet with the cardiac team, the palliative pain doctor, and the psychiatrist to validate his wishes and ability to make this decision. That meeting took place, and the head cardiologist for the team agreed that my husband had an "ethical right" to have the LVAD de-activated but stated that he would not participate. It was then decided that the palliative care physician would admit him to the

palliative care unit and manage the de-activation with appropriate sedation and pain medications. My husband did not want to suffer at the time of de-activation. He also worried about what people would think. The ethics consultant explained that de-activating an LVAD is not legally nor ethically considered "suicide" and that he would be dying of his underlying heart failure; this was no different than a patient who requests to have a ventilator removed to allow death.

My husband set the date for his de-activation, and it was completed on May 22, 2017, with the palliative care team and no complications.

I was in touch with the ethics consultant throughout this difficult 14-month period, often by phone or in person, as was my husband. Knowing that she was there to answer questions, help us navigate this journey, and not be afraid was of great comfort to us. She was there during the de-activation with my family and me and helped us through all the way. I continued to call her after my husband's death, and she helped to reassure me that it was his wish and right, and the best thing for him. We are still in touch today, five years from that date, and I do not think any other hospital service remains "with you" consistently throughout the course of such a traumatic and complex journey toward the end of life. We needed the constant resource to reassure us we were doing what was best for my husband, for me, and the kids. The ethics consultant was so kind and warm, and we didn't feel alone . . . we felt heard. My husband would still be suffering if we had not been guided to call Ethics.

I will always recommend to others that they should utilize the Ethics Consultation Service at hospitals if they are facing difficult decisions, but I would also recommend that more patients and families should be made aware of the service, as we would never have known if not for the palliative care doctor's referral. There should be more ethics consultants involved in the care of patients and families who are struggling with difficult decisions in all healthcare settings.

*NIB policy allows authors to publish anonymously when stories considerably contribute to a symposium but contain highly sensitive information that cannot be*



*de-identified. However, stories are never submitted or accepted anonymously, and all authors sign our publication agreement, which upholds standards for responsible authorship.*



## Unbefriended

Jean Watson

“**C**an you be a friend to someone who needs one right now?” That probably wasn’t the question that our hospital clinical ethicist asked, though that is what I recall. It sounded like something my mother would encourage me to do. It sounded like something I would like to do. It sounded easy. It was none of that and so much more.

Two weeks earlier, a man was found down in his apartment, unresponsive. He had had a stroke. He was hospitalized in our ICU on a ventilator. He had no family or friends to speak on his behalf. Decisions needed to be made. Should he undergo surgery to place a tracheostomy and feeding tube to continue his life?

The hospital hired a private investigator who performed yeoman’s work, trying to find someone who knew this man, someone who might be able to share information about his values so that we could act in accord with them. Remarkably, no one was found. The patient had been retired from work for more than a decade. Though he rented an apartment, his landlord did not know him. No family was discovered. No friends came forward nor were identified. No medical records were uncovered. He had not seen a doctor or visited a clinic or hospital in the area until now. He was a solitary person, a human being without close relationships. His apartment was unkempt; beer bottles were strewn about the place.

The clinical team requested an ethics consultation. Though the hospital does not have a formal policy for decision making at moments like these,

our ethicist is well-versed in a variety of ways these circumstances are handled. Sometimes a treating physician functions as both the attending and a surrogate. This can be fraught with potential conflicts of interest. Unconscious bias could influence one’s thoughts about the value of a life and the cost to sustain it. Sometimes the attending provider presses on with therapies regardless of the likelihood of successful treatment. This choice fails to acknowledge individual autonomy. It fails to weigh the suffering required to live another day. It sidesteps the thorny issues that are discussed everyday between providers, patients, and loved ones.

The ethicist gathered a group to serve as informal surrogates for this patient. Three of us agreed to act as friends and decision makers for this man, helping the treatment team determine next steps. The ethicist provided a few rules and much oversight.

We met for a family conference. The intensivist and neurologist shared the diagnosis and treatment that the patient had received. They detailed information about the decisions that needed to be made. The patient’s nurse, the social worker, and the spiritual care intern attended the meeting to watch the proceedings and contribute to the discussion. We three, the patient’s friend group, were invited to ask questions. We had some.

I am a hospitalist, an internist working in a hospital caring for patients. I have done this work for 25 years. I know the intensivist and the neurologist well. We have worked together, caring for many people over the years. My two surrogate partners were a nurse and a chaplain. The nurse had decades of professional experience, including in the intensive care unit. The chaplain was experienced in her work and comfortable with the challenges that arise in a hospital.

The three of us had a robust discussion. I shared what most patients tell me when I ask about resuscitation status. “I don’t want to be kept alive on machines,” or “I don’t want to be a burden.” The ethicist gently reminded us that we were tasked with making a decision on behalf of this person, irrespective of what others would decide for themselves. It was challenging to tease out clues

that could guide us to what this man might choose for himself.

Because of the location of his stroke, the patient was not expected to regain consciousness. He had been off sedation for more than a day and had not woken up. For the rest of his life, he would be institutionalized, ventilator dependent, and sustained with nutrition administered via a tube into his stomach. He would never again be awake, breathe on his own, speak, or enjoy a meal.

The treatment team presented two choices, two paths, for us surrogates to consider. Option one was to give the patient a tracheostomy and surgically placed feeding tube to sustain his life. Alternatively, the treatment team would remove the ventilator and stop administering nutrition including water. They would treat him with medications to manage his discomfort, primarily pain and anxiety. He would die in the hospital. Neither is a good choice, though after deliberation, the surrogacy group decided that this gentle man, should not undergo surgery or receive more treatment to sustain his life. The chaplain said it most eloquently when she shared that the thing that makes him most human was already gone.

We reconvened with the intensivist and the neurologist to share our decision. They agreed with it. It was reassuring that there was consensus.

Following our family conference, we surrogates participated in a debriefing with the ethicist. We discussed the patient and the exercise of being an informal surrogate for someone who has none. We were asked if the patient's lack of social support, messy apartment, or empty beer bottles contributed to our decision making. The condition of his apartment was informative regarding his last days at home. Perhaps this was where and how he spent all his days since retirement, but there was no way to know that. We did not discuss his cleanliness or possible alcohol abuse. However, we did discuss his lack of social connections. This influenced our decision. This person was seemingly without human relationships. We inferred that he preferred to be alone. He, or someone like him, would not want to be institutionalized receiving care from others for the rest of his days. Also, there was some evidence

that the patient had not sought medical care for several days after his health deteriorated. When he was still able to act on his own behalf, he had not sought care.

Once our debriefing was done, the ethicist invited us to meet the patient. It had not occurred to me that I would meet him. I had not reviewed his chart; it was one of the requirements of participation that I learn about him from the treatment team only. I was agreeable to meet him, though was unexpectedly gripped with anxiety. My concern was that I was ending a man's life.

You see, this story takes place in Minneapolis, Minnesota in early June 2020. The hospital where I work is less than a mile from the place where George Floyd was murdered days earlier. The air outside hung heavy with smoke from nearby burning buildings. Anger and grief over the cruel and senseless death of a man gripped the community including all of us at the hospital. The warehouse that held the hospital's very limited supply of PPE was threatened by fires. This confluence of crises was overwhelming. Floyd's murder was the only thing that had shaken loose the grip that COVID-19 held on us. I shared my worry with my surrogate partners, and both acknowledged my discomfort. As we walked to the patient's room, I still thought that we had made the best decision for this man.

The patient was resting on his back, receiving breaths from the ventilator without sedation. We spent several minutes with him in silence and talking to him while holding his hand. He remained quiet, eyes closed, not moving. There were no indications of discomfort: no furrowed brow, no heart palpitations, no respiratory distress, and no sweat. To tolerate a ventilator without any sedation confirmed that his stroke was extensive. He was completely dependent on others and disengaged from his body and surroundings. Following the family conference, this man was extubated and died several days later in the company of hospital personnel.

Even though this situation is rare, it is wise to have hospital policy governing how these waters are navigated. Prior to my hospital employing an ethicist, there was no standard approach, no

guidance for these decisions, and no support to the providers and the care team. Our ethicist provided the guidance and support for this circumstance. Though my friendship with this patient was brief, my friendship with the other surrogates is long-lasting. We occasionally pass in the hallway and always acknowledge one another as the friends that we became, the day we befriended a stranger.



### **The Clinical Ethics Consult: Transforming Ambivalence to Action**

Eve Makoff

**A**s palliative care practitioners, we're good at diffusing explosive family dynamics and holding space for patients and families in emotional crises. We also help everyone involved with the care of seriously ill patients focus on what is best based on the values of the most important person in the room; the one in the hospital bed. So, when we call for a bioethics consultation from a clinical ethicist, it's because something has gotten stuck or, perhaps, we could benefit from a reframe—or a new set of eyes to ground the scenario or the emotional miasma that tends to linger and drift when on the cusp between life and death.

In the 1990s, at least in my medical school and residency programs, medical ethicists in the hospital were not often a part of direct patient care. They were like philosophers, available to curbside and advise on ethically murky cases but at a distance from the trenches. These wise, generally older men with white beards parceled out all potential ethical sides of the case, leaving us to decide the best way forward. The Socratic Method<sup>1</sup> was often employed, so we were left to grapple with the ambiguity that

exists in most issues about what's right or wrong. It sometimes felt frustrating but now I realize the importance of honing the skill of tolerating the feeling of not immediately knowing the best way to proceed in the practice of medicine. As it turned out, by the time I started practicing palliative care in 2013 and began to regularly collaborate with what was then our clinical ethics partners in care, our ethics director Dr. F was also a wise older man with a white beard. But he and the rest of his (non-male, un-bearded) team didn't have that untouchable ivory tower kind of protection around them. They were accessible. They dug into the hard stuff right alongside us when they were asked to get involved.

One time when I consulted ethics on a case, I'd been navigating a switch from practicing internal medicine to palliative care. At the time I was dealing with personal ambivalence—feeling mired in the heaviness that infused my workdays and unsure if I could take it. It turned out that a clinical consultation, and a family meeting with Dr. F, helped in more ways than one.

That day, we gathered in the medical intensive care unit conference room. It doubled as a storage closet, so the team, including our patient's family, dragged in chairs and stools and crowded around the oblong melamine table next to the whiteboard with half-erased arterial blood gas calculations. We hunched together to see where things stood and make some essential decisions.

As we do in family meetings, we reconfirmed our roles on the team: ICU fellow, resident, and medical student. Nurses fluttered in and out as their patient care allowed. The patient's daughter with silver-streaked hair was in attendance, as well as her son, who was slumped in his seat. Both looked sleepless and frazzled. And finally, Dr. F and myself—clinical ethicist and palliative care doctor—gathered. Dr. F then took the lead, announcing our intention to come together and discuss what was best for our patient—their mother. Dr. F then requested a medical update from the ICU team.

"Mrs. Lyons is on a ventilator. She's sedated and medicated for pain. But her organs aren't doing well. She's not getting better," the resident read off of his white paper of scribbles.

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<sup>1</sup> *The Socratic Method is a form of shared dialogue between individuals, based on asking and answering questions to stimulate critical thinking and draw out ideas from students.*

Suspended between her life and her death, Mrs. Lyons lay unperturbed but unreachable, and her family was agonizing about what to do. For days our palliative team had discussed the options with the family—we could cut back on the medications and try to wake her up, knowing she'd likely have considerable pain, and to what end? We could reconsider that surgery for her infected bowels, but she'd likely not survive.

Or we could let her go—discontinue the ventilator and likely let her die.

They could not decide.

The family seemed to need more help than we'd been able to give. They hadn't had those pre-morbid conversations or completed those documents with their mother about what she was willing to tolerate in order to stay alive. Without those words clear in their minds, they couldn't move forward. She didn't like to talk about death, and they followed her lead. When we met in that room, the daughter and son were stuck, suspended, like their mother.

I reached out to the clinical ethics team. By zooming out and re-contextualizing the family's ambivalence, fears, or guilt about their situation, I hoped they could find some peace with whatever they decided. Above all, I hoped they would know they weren't alone in struggling with their enormous questions and feelings in the milieu of ethical dilemmas that have existed since time immemorial when it comes to life and death.

"Tell me about your mother," Dr. F said.

"She is a strong woman, a proud woman. She wouldn't want this. I know she wouldn't want this," the daughter replied quickly, her brother shaking his head slowly in agreement. "And yet . . ."

We all waited silently for some time for her to go on, but we already knew a decision had been made. It wasn't that our team hadn't asked the same question before and gotten the same description of her ferocity and pride. But this time, it was different. The daughter was now able to connect who her mother was with what she would want in this moment. It was as though by gathering us together, pausing our worlds alongside theirs, we created a community of caring and attention. This allowed the family to admit what they'd been unwilling to

say at the bedside or in the small grieving rooms just outside the ICU: It was time to move on. It was what *she* would want. In that family meeting space, the discussion transformed paralyzing grief and everything attached to it into the process of mourning.

A tear fell on the daughter's cheek as she looked up at Dr. F and me sitting together before her. She finally spoke: "How do you do this all day? How could you both possibly have this as your job?"

Speaking for both of us, Dr. F replied quickly: "Because there's no bullshit in this room. It's the only place where there's no bullshit."

I was stunned by the brute honesty, the somewhat crass language, of my wise friend and colleague in the middle of the ICU, but I felt something else too. I felt somehow I'd become unstuck too—like the family we were treating. Perhaps I too was moved by that moment of attention—by the profoundly transformational impact of the deep witnessing of grief. And, like them, I was changed and able to move past my own ambivalence to realize I was exactly where I belonged.



### Side Stepping The Issues: Disappointment With An Ethics Consult For A Medically High Risk Patient

Brent R. Carr

Months of severe symptoms were a blur—hour after hour of suffering. Sleep is her only respite. Her 5-word diagnosis, "treatment-refractory depression with anxious distress," seemed too orderly, like a flattened 2-dimensional strip of ribbon that simply ironed out all the chaos and confused distress roiling within her. Anyone entering the psychiatric unit early in the morning could hear her near-breathless sobbing, calling for nursing help, repeatedly pleading to anyone who would listen that she was dying. By afternoon, her wheelchair would be situated off to one side of the milieu to prevent agitation of other

patients. From there, she would summon them with small gestures or brief, incessant outbursts to save her, that her body was decaying, withering before them. Such is the torment of nihilistic delusions. She flailed her arms, rocking back and forth, lamenting that no one would help. Although she possessed full leg strength, she refused to stand from the wheelchair, fearing collapse. These distressed pleas were sustained well past each dinner, the anguish echoing from her room, and during her evening shower. Sometimes a pillow-muffled sigh and silence would disclose when her torments became engulfed in sleep.

Two years prior, she had a similar episode that lasted almost 3-years. It had failed to respond to months of psychotherapy and more than 15 medication trials. That time, she had cried with happiness after the mental illness went into full remission after only a three-week course of electroconvulsive therapy (ECT). She described this as her miracle. But as miraculous as the ECT was for her, it was problematic. She is a high-risk patient with ongoing hypertension and Wolff-Parkinson-White Syndrome, a condition that leads to an inappropriately fast pulse from aberrant electrical pathways in the heart. During the final week of ECT, she experienced a marked blood pressure surge that led to severe cardiac pathology—Takatsubo’s cardiomyopathy. This is also known as “stress cardiomyopathy” or “broken heart syndrome,” befitting the vexed emotional state she had been in. The cardiomyopathy resembled a myocardial infarct, and it took several months for her to fully recover. Unfortunately, this prevented the use of ECT as a relapse prevention treatment. By one-year post-ECT, her systolic left ventricular dysfunction had resolved, and her ejection fraction (the heart’s pumping efficiency) had normalized.

Now, once again, she was treatment-resistant, and ECT was the treatment of choice. The risk stratification for ECT encompassed her prior Takatsubo’s cardiomyopathy, which has a small but known chance for recurrence. This made her a high-risk patient. This risk was convoluted even more by her depression-induced psychosis, wherein she believed that she was dying, that meds were

poisoning her, and that ECT would kill her from a heart attack. Before the psychiatric team consulted the ECT service, a mental health court had already ruled regarding her lack of capacity for her medical decisions. The court had authorized her husband as her proxy with authority to consent for her medical care, including for ECT. My role in this case was as the ECT proceduralist from the neuromodulation service who had been consulted by the primary team. The husband was an informed individual and signed consent for ECT. These events all coincided with the primary attending’s departure on scheduled leave. There was now a new covering attending.

The resident psychiatrist was apprehensive about ECT and deliberated that the patient was at least able to identify potential risks of ECT—even if exacerbated by a nihilistic delusion. The resident speculated that perhaps the patient should at least be able to refuse ECT, given her previous cardiomyopathy. The newly arrived attending deferred a response regarding her concern and stated it had already been decided by the “team.” This amplified doubt. The medical students sensed the resident’s apprehension and felt confused about whether the patient should receive ECT or not. This dynamic quickly spilled over into nursing discussions, where some were now hesitating about the decision. The cohesiveness of the psychiatry treatment team was compromised.

As the attending who was to perform the procedure, I felt it important these hesitations were at least discussed, if not resolved. As such, I suggested that the psychiatry team consider an ethics consultation, as this may offer some assistance and help deliberate over the emerging mixed emotions surrounding the case. The resident and I discussed that it might afford some clarity or affirmation regarding the capacity and consent issues that she had brought up. This would also allow a neutral party to further evaluate the difficult decision the team and her husband had made for his high-risk spouse. I encouraged our trainees to express their apprehension and fears, which naturally emerge when making decisions that could result in morbidity or mortality. The ethics consult would promote further



discussion about these challenges and, hopefully, foster stronger team cohesiveness. The psychiatry team attending, resident, and med students were enthusiastic after it was suggested.

The university provides a lithe Ethics Consultation service that is available at any hour. It is diverse, comprising a few ethics-specialized attorneys, emergency and critical care medicine physicians, geriatric medicine specialists, and clinical psychologists. Its mission is also clearly defined on its Ethics Consultation webpage. It declares its goals are founded on the American Medical Association's standards, where it provides informed and deliberative care, responsiveness to both provider and family, those seeking assistance with conflicts and concerns arising in healthcare, facilitation of discussion, and providing education. Although I have never used their services before, their page states they will allocate their time involvement based on the unique needs specific to the circumstance.

Forty-eight hours later, I was asked to proceed with ECT. The resident reported the Ethics Consult was on the chart. It was a succinct summary that stated all the necessary legal obligations had been met, the established lack of capacity had been appropriately documented, attempts to "avoid harm" were present, and affirmed husband was legally able to consent. The Ethics team signed off but stated they were available again should the need arise. According to the resident, the Ethics Consultation team had met with the husband but not the team. Brief, simple. Oddly, all team members and students now verbalized how comfortable they were with proceeding with ECT. All hesitation or concern had fully and immediately dissolved after this perfunctory consultation. I attempted to process with the residents and students why there was such an immediate resolution to their concerns. But I was met with silence.

My first inclination was the feeling of disappointment, which I had inappropriately and initially attributed to the brevity of the consultation. It had responded to what was asked of it. Perhaps it was my disappointment in the trainees' seeming disinterest or unwillingness to absorb themselves into a philosophical endeavor. Or was this a displacement

of my failure to engage our students and residents in an ethical debate? Was this simply the sequelae of the time constraints of a hectic service? The ethics consult seemed depreciated somehow—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.

The deference to the Ethics Consultation as a finality felt more paternalistic than collaborative. Possibly a mere affirmation from a neutral party was all that was needed by the primary team to alleviate the hesitation. Had the Ethics Consultant served as a surrogate leader if the team dynamics were weak? Did the consult mitigate angst by diffusing ownership of a potentially bad outcome? Notwithstanding, the decision had become more palatable after the unceremonious consultation.

While on call a couple of years later, an intern called me one evening, hoping to process a case. There was a medically compromised elderly patient who appeared to lack the capacity to make medical decisions, and her son was serving as a proxy. But throughout the patient's hospitalization, various team members had growing concerns about the son's capacity. He was manifesting signs of a possible mental illness that was calling his judgment into question. Once again, there was a fractured team, with the Medicine service sometimes accepting the son's medical decisions and at other times the patient's decisions. This appeared confusing to the trainees, who wondered if the inconsistency was due to selection bias. They contemplated how to properly assess or accept such decisions. This was further complicated by the psychiatry consult service that had reservations about both the patient and son's capacity and wondered if an independent proxy need be assigned. The nursing staff had voiced their frustration over not knowing what limits to place on the son who was the proxy. Medical students confidentially articulated their confusion and concern to only the resident but were apprehensive about expressing their thoughts at the team level.

I proposed that the Psychiatry Consult service should recommend an ethics consultation. This time, I advised the intern to call the Ethics Consult

team first to process the case verbally and discuss what they could offer. She did so, and the Ethics team responded promptly. They agreed it was an appropriate use of their services and would be pleased to assist. Psychiatry Consult service made the recommendation. Two days later, I asked the intern how the Ethics Consultation had gone. I was told the attending stated that no ethics consult was needed so one was never placed. The patient was to be transferred to a skilled nursing facility later that afternoon. There was one line written in the discharge summary that stated the social worker was to contact adult protective services.

The initiation of the ethics consult may be an underestimated barrier. Many physicians might be unfamiliar with what an ethics consultation could offer. There may be a perception that Ethics Consultations must be reserved for catastrophic or high-profile cases. Yet it need not be saved only for fantastical cases. Our ability to identify a fracture within our team is occasionally limited, and we should be willing to embrace a second opinion or solicit input from a neutral party. For the more experienced clinician, the Ethics Consultation may be personally less necessary, yet the consult should not be considered their exclusive prerogative. Perhaps the consult initiation hurdle might also arise from the mistaken notion that consulting Ethics might suggest a deficiency in our ability to manage ethical dilemmas. Or perhaps there is some unconscious fear of scrutiny over our cases' management. As such, Ethics Consultations are only as good as our willingness to engage in them.



## **My Father Dies Alone**

Anonymous One

**T**his is a story about my dying father, me, and our experiences with clinical ethics consultation (CEC). Some details have been changed to protect anonymity. I am a professional bioethicist

who has served for decades on hospital ethics committees, so I have a twofold point of view—that of a son with a dying parent, but also that of a trained bioethicist.

At the time of these events, my father was over eighty. He had numerous medical problems, all well-managed, and he was not actively dying. My father's life was enjoyable. He liked going to the movies, visiting with friends, and taking short trips around the city. He loved to eat out and to have my wife and me over to his house to play cards. His biggest barrier to greater enjoyment was reduced mobility, which made his life somewhat confined and narrow.

About a year into the pandemic, my father developed COVID. He was hospitalized at a major, well-funded medical center, which I will call Metro. Metro's hospital had about 450 beds and was not triaging patients. The doctors treating my father judged that, because of COVID and his comorbidities, he was inevitably dying. Nothing that happened subsequently ever led me to think they were incorrect.

I could arrange calls with my father while he was in the ER, but Metro prohibited family visits unless the patient was dying. On a call with the attending, I requested to visit my father. Metro was a long distance from me, but with notice, I could drive and make the visit. The doctor refused. The doctor—who I will call Dr. Stewart—said that he was certain my father would recover well enough to be discharged, then live “for weeks” before dying at home. I could visit my father after discharge, Dr. Stewart said. I explained that I was worried that Dr. Stewart's prediction could turn out to be incorrect and that I would miss my last chance to see my father. Dr. Stewart again refused to authorize a visit.

Most patients would have been largely helpless at that point. Metro did nothing to advertise whether they offered ethics consultation, patient advocacy, or any similar service. Because of my professional background, I asked Metro's operator to page the head of the ethics committee. He did not call me back. I went through this same process several times but never received a return call. Nothing on Metro's website said anything else about

an ethics committee or ethics consultation. Typing “ethics consultation,” “ethics committee,” and related terms into Metro’s website search engine to this day produces zero results.

I spoke with Dr. Stewart again. I revealed that I was a bioethicist and offered to send him the extensive literature on how bad doctors are at prognostication, despite their confidence that they are good at it. (I put the point far more diplomatically when speaking to Dr. Stewart.) There was no uptake—it was like speaking to a customer service representative who repeats the script over and over. I asked for an ethics consultation. Dr. Stewart said he would not request one because there was “no ethical issue”: this was simply a *medical* question about whether my father would survive to discharge. I pointed out the obvious ethical issues, but Dr. Stewart still refused.

Technically, my father survived to discharge, in the sense that Metro was able to load him into an ambulance and drive him to his house. He died almost immediately after arriving, and well before any family could make the lengthy drive to see him. After he died, I remember my last phone conversation with him. His final words were, “I wish I could be with you to hold your hand.” He wanted me to be there to comfort him, and to this day I live with the overwhelming guilt that I let him die alone, frightened, and in pain.

Looking back, I’m not sure why I gave in after Dr. Stewart refused an ethics consultation, but my best guess is that, like all children facing the death of a parent, the stress, anxiety, and pain were simply overwhelming. And in such a state, the mind clings to anything that will take away the pain and anxiety, whether that’s rational or not. In my case, I was not only experiencing the pain and anxiety of anticipating my father’s death, but the vastly *increased* stress of having to argue with my father’s attending physician. When I gave in to Dr. Stewart, it meant those arguments would finally end.

Like all children who lose a parent, I have grieved, wished, regretted, and cried. But because of my work as a bioethicist, I have also reflected on the lessons my father’s case teaches us about CEC. I’ll divide them into general categories:

1) First, some lessons about availability. My story strongly confirms that CEC should be widely available and clearly advertised. Only a fluke in my background allowed me to know that CEC might even exist at Metro.

More importantly, patients and family should *never* be put in a position where an ethics consult must be routed through a person involved in the dispute. In my case, I could only request a consult by getting Dr. Stewart to call the consult himself—essentially, to call a consult directed *at* him. As one bioethicist said to me, the system at Metro is like a system where one can report sexual harassment only by convincing *the person harassing you* to file a report against themselves. What a terrible system.

2) My father’s story also points to lessons for providers. One is that this incident and many, many others I’ve witnessed on ethics committees tell me that healthcare providers are wrong about things far more than they know—a result backed by empirical studies. Despite that, many are also enormously resistant to admitting that they might be making a mistake. In fact, in more than 20 years of service on multiple ethics committees, I have never heard any committee or committee member say, even once, “I guess we were wrong and the patient was right.” And in decades of cases, could the patient have *always* been wrong? Obviously not.

It would take a psychological study to determine why healthcare professionals are so resistant to accepting their own fallibility, but one possibility is that healthcare professionals are asked to make important, life-changing decisions on a routine basis. One simply cannot do that job if one is second-guessing oneself all the time. Fair enough, but a problem arises when the confidence becomes *too* high.

Related to that, my experience, both as a patient and as a bioethicist, is that medical professionals have a tremendous distrust of patient’s opinions about anything even vaguely related to medicine, ethics, or even some of the patient’s own subjective reports. They’re tired of patients consulting Dr. Google, and they assume (perhaps rightly) that in the vast majority of situations, patients are unlikely to know something of significance that they do



not. This makes them incapable of entertaining a patient's contributions or objections.

The problem of excessive confidence is especially acute when ethical considerations arise in medicine. It's well known among bioethicists that medical professionals have trouble seeing when their judgments have moved beyond pure medicine and into the realm of ethics. For example, doctors often describe a treatment as "futile" when it leaves the patient in a severely debilitated state, but labeling such a treatment "futile" is not a medical judgment—it is a judgment about what kinds of life are worth living. In these cases and others, professionals often cannot see that they have crossed over into the realm of ethical value.

All of these problems were at work in my case. Dr. Stewart seemed incapable of accepting that his prognostications about my father's lifespan could be uncertain or that I might know of research about medical prognostication that he wasn't familiar with. Most importantly, since his judgments could not possibly have been 100% certain, there was an ethical question of whether a hospital should allow a child to have what *could* be a last visit with their dying parent. When is the chance of death high enough that infection control procedures should make room for family to visit? That is the issue, and it is not a medical one. Dr. Stewart could not see that.

3) A third set of lessons concerns the healthcare system. My story identifies several obvious problems with Metro's policies and procedures. But why do these problematic policies and procedures persist?

I do not think market competition cures all ills—in fact, I have published widely on the problems with market-based insurance systems—but I do think one reason problematic policies persist is that the healthcare industry lacks normal market competition. That fact is widely accepted by health economists, but healthcare professionals often resist it. In fact, healthcare professionals are often quick to say that their first-hand experience tells them that the healthcare industry is highly competitive—even cutthroat. They are personally under constant strain and pressure, executives constantly claim that it is a struggle to remain profitable, etc.

All those things are true, but they are not the kind of competition I have in mind. A little economic theory will be useful. In most industries, if consumers feel they receive poor service—for example, from their financial advisor or their car mechanic—they can easily take their business elsewhere. This is why businesses address consumer needs: they will lose money if they do not. However, healthcare institutions are often partly or substantially insulated from these forces. For instance, a hospitalized patient who feels his concerns are being ignored by the staff cannot feasibly check himself out of the hospital in order to punish the hospital economically for mistreating him. In fact, depending on his insurance coverage and place of residence, he may have no real choice but to use the same hospital for services in the future, no matter how badly the hospital treats him this time; and he may also have no feasible way to change his insurer, even if other insurance plans would grant him access to different hospitals. (We should not forget that many Americans have no realistic choice of health plan or hospital at all.) Moreover, even if individuals have, in principle, a choice of providers or hospitals, there are tremendous problems with switching from one to another. For someone with multiple medical problems, for instance, it is no small thing to attempt to find all new providers, transfer all of one's medical records, and so on. And of course the switch might not improve things either. A patient entitled to "choose" another hospital or insurance provider might only have the "choice" to use one that is the same or worse.

When consumers cannot feasibly take their business elsewhere, hospitals do not have economic incentives to change. And health economists have shown that healthcare markets are less than competitive in many ways, and that many hospitals and large insurers are *de facto* oligopolies.

In my case, Metro is insulated from consumer feedback for the obvious reason that now that my father is dead, there is no way for him or me to economically punish Metro by withholding our business. But Metro is likely to be insulated from market forces even when the patient lives. I suspect many families have been poorly treated by Metro's

policies and by doctors like Dr. Stewart, but for reasons given above, the odds are that many of those families cannot feasibly take their business elsewhere. This insulates Metro from normal market forces and means it has little incentive to improve its services.

In the end, then, clinical ethics consultation could not help me, for the simple reason that Metro made CEC inaccessible. I fear that in current healthcare markets, Metro and its personnel have little incentive to change.

*NIB policy allows authors to publish anonymously when stories considerably contribute to a symposium but contain highly sensitive information that cannot be de-identified. However, stories are never submitted or accepted anonymously and all authors sign our publication agreement, which upholds standards for responsible authorship.*



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

Michelle Prong

**Editor's Note.** The details of the patient case presented below have been modified to protect the family's privacy. Despite these modifications, the author has made every effort to preserve the story's clinical, social, and ethical nuances.

The patient was born at 31 weeks with Trisomy 13 and lived her entire life in the NICU. She was born to a 16-year-old mother (who I will call M.H.) as the result of an unintended pregnancy. This child was just about a month old when I became part of her care team. The patient was born with a severe congenital heart defect that our pediatric cardiac surgery team—as well as surgical teams at multiple other academic

children's hospitals—determined to be inoperable. Because of her severe heart defect, she required significant respiratory support throughout her life and continuous IV medications to keep her organs perfused.

When I came on service, M.H. visited irregularly and depended on her mother (the patient's grandmother, who I will call D.R.) for transportation. Social work had arranged for M.H. to have daily transportation to the hospital after school and work; however, M.H. was denied the opportunity to spend the night with her infant. It was against hospital policy for minors to stay overnight as visitors, and additional visitation guidelines related to COVID precautions were also in place at the time. As her biological mother, M.H. was designated as the patient's healthcare decision-maker. The inability for M.H. to stay overnight on the basis of her age despite being the patient's parent and healthcare decision-maker generated significant moral distress for several members of the care team. The social dynamic between M.H. and D.R. was such that D.R. was far more participatory in rounds and goals of care conversations, and M.H. was almost always reserved and withdrawn. On multiple occasions, different team members attempted to have conversations directly with M.H. She either was not engaged in the conversation, would answer with short phrases, or, when D.R. was present, would defer to D.R. to speak for her.

Throughout the patient's life, D.R. seemed to be the driving force behind most treatment and goals of care decisions. In multiple conversations I had with the family, both one-on-one with M.H. and jointly with M.H. and D.R., it was made clear that they wanted "everything done" and were hopeful for "a miracle." D.R. emphasized that she didn't want anyone to "give up" on the patient and wanted to exhaust all possible options for a cure. Overall, our team had become increasingly concerned that the medical decision makers for this patient did not comprehend the very poor prognosis of her congenital cardiac anomaly, either with or without surgery. As the medical team, we would be subjecting this child to harm that would be unlikely to change her prognosis.

Our NICU team, as well as various other teams, discussed the case repeatedly without a resolution that felt satisfactory. A complicating factor for this particularly socially and ethically challenging case was that the team turned over relatively frequently during the patient's long-term stay, making it difficult for each successive team to understand what had already been done for this patient and her family. We decided to seek help from the Clinical Ethics Consulting (CEC) service. My expectation for the CEC service was that the consultant would help our team think differently about both the clinical and social elements of the situation and help us come to a resolution since we could not figure out a good solution on our own.

Our consult question for the CEC was fourfold: 1) Did the patient's mother meet criteria for an emancipated minor (to get around the visitation policy), 2) Is M.H. the appropriate healthcare decision maker given her lack of engagement in goals of care conversations and perceived understanding of the severity of her daughter's condition, 3) If M.H. is indeed the most appropriate healthcare decision maker, to what extent is it appropriate to involve D.R. in the medical decision-making process, and 4) Is it unethical to deny the patient's mother from staying overnight with her if she so chose?

The CEC was extremely helpful in gathering all pertinent information to the case prior to providing guidance. The CEC spent about a half hour on the phone with me to fully understand the problem and the complex dynamics of the social situation. She asked questions to determine what had already been done on our end to explore each of our consult questions and maintained a posture of curiosity and humility throughout the process. She then came to meet with the patient's mother one-on-one and then discussed the case with our team. What I appreciated most about the way the CEC handled the consult was how she empathized with how difficult the situation was for everyone involved, including the care team, when providing recommendations.

The answer to the first question was fairly straightforward; M.H. did not meet criteria delineated by New York State to be considered an emancipated minor. The answer to the second and

third questions were also fairly straightforward; the law states that the biological parent of the patient, regardless of the parent's age, is the designated decision maker. And that the medical decision maker may involve whoever she wishes to aid her in that process. Without evidence of abusive or neglectful behavior on the part of M.H., there was no room for us as the medical team to decide whether or not she had the insight to appreciate the medical and social complexity of the situation. And there was no room for us as the medical team to determine who M.H. could and could not involve in decision making. Rather, it was our role to facilitate a process for M.H. that supported her in making decisions for her child that aligned with her beliefs and values.

With respect to the fourth question, the CEC ultimately helped us come to the conclusion that prohibiting the mother and healthcare decision maker of the patient to visit overnight on the basis of a hospital policy was something we needed to push back against more strongly. With the assistance of the CEC, we figured out a way for M.H. to stay overnight with the patient if she so chose.

I wish I could say that because of our efforts M.H. became more engaged with the care team. I rotated off service not long after consulting clinical ethics and so was not familiar with how communication between the team, M.H., and D.R. progressed throughout the rest of the patient's admission. However, I valued my experience with the CEC in this case because of their ability to help us think differently about a challenging case and help us take a collective step forward, albeit a relatively small one. Because of my very positive experience working with the CEC in this case, and ultimately helping us make something happen that was in the best interest of our patient, I have enthusiastically recommended clinical ethics consultations to my colleagues. I have recommended this service to my colleagues because of how thoughtful and empathetic the CEC was not only for our team but also for the patient and their family. The service helped us think differently about the problem by employing a different perspective from which to brainstorm solutions.

Through the process of consulting clinical ethics, I have also learned the difference between

consults most appropriate for clinical ethics and differentiating those from consults most appropriate for hospital legal counsel. I appreciated the clear boundary that the CEC had between providing ethical guidance and providing legal guidance. This may be a helpful distinction for other providers requesting clinical ethics consultations in the future. Despite the complexity of the above case, the clinical ethics consult service helped us clear the path forward for the patient, at least in the short term, and help empower team members experiencing moral distress.



## The Healing Power of an Ethics Consult

Laura J. Hoeksema

**O**ur interdisciplinary team was inhaling and exhaling conflict, frustration, anger, confusion, guilt, and feelings of helplessness as we cared for a 21-year-old woman who was dying. We had regular disagreements about how our team should best care for her. She was receiving hospice care and had complex medical, psychosocial, physical, and emotional needs. She was frequently transitioning between hospice care at home, living with different family members at different times, and hospice care in the hospital due to uncontrolled symptoms. This led to her having an inpatient hospice team made up of me—her physician—and a nurse, social worker, and chaplain and also an outpatient hospice team with a different physician, nurse, social worker, and chaplain. All of us cared for her regularly in our respective settings. Members of the two care teams advocated passionately for what they thought was best for her. At times, team members were advocating strongly for conflicting interventions. Every member of both teams experienced moral distress related to some aspect of her care.

How could we move forward in a unified way to provide her with the best care possible when there was uncertainty and disagreement within the

teams about whether we were providing her with ethically appropriate care?

Several questions arose about her care:

- What is our responsibility in protecting a vulnerable patient when there is concern she's being taken advantage of by others?
- How do we address concerns about possible opioid diversion? Was a dying patient not receiving the pain medication she needed because someone else was using it?
- How do we address household members smoking in the presence of someone on oxygen?
- Do we honor a dying patient's wish to live in an environment that we're concerned is unsafe for her and our staff?
- When team members receive contradictory information from a patient, how do we develop a common understanding of the situation?
- Was it appropriate for our team to spend hours and hours caring for her each day which prevented us from caring for other patients who also needed our support?
- What is our responsibility in relation to supporting her family with their financial and legal concerns?

We placed an ethics consult to help us think through the answers to these questions and address the intense moral distress of team members. After listening to us share our experiences, the ethicists acknowledged the complexities of caring for her and affirmed that we were doing a good job. This acknowledgment from someone not directly involved in caring for the patient was meaningful. Having colleagues, who weren't impacted by the emotional intensity of caring for her, empathize with us helped us gain some perspective in the swirling tornado of our emotions.

Moral distress was running rampant. Some team members were distressed that we were giving the patient too much autonomy to make decisions they felt put her at risk. Others felt we should restrict her autonomy significantly to protect her. Some were distressed by family members smoking near her when she was on oxygen. Others were distressed that the investment of time in caring for her was so great that we couldn't care for other patients in ways they deserved. Team members were very passionate about their beliefs about what was right and wrong as we cared for her.

The ethics consultants addressed the conflicting ethical values and helped us feel more comfortable with the plan of care we developed together. We were asked thoughtful questions to help draw out sources of moral distress. We were given new ways of thinking about conflicting ethical values, which helped us understand the underlying reasons for the conflict our team was experiencing. Highlighting the ethical values that were in conflict and helping each of us understand that the specific aspects of her care that we found distressing were related to our personal values, helped decrease the intensity of disagreements and frustration. The ethicist's ability to share this knowledge with our team was powerful. Our team realized that we weren't frustrated or upset with each other. We came to understand that because of the values we hold so dearly and prioritize differently, we had divergent perspectives on her care. This experience helped us clarify our individual values as we reflected on which of our values we felt were being disregarded or infringed upon.

The hospital was a much more controlled environment than the patient's home leading to very different experiences caring for her in each setting. Prior to the ethics consult, I didn't fully appreciate how uncontrolled the home environment was and felt for our home team. This knowledge enhanced my empathy and understanding for my colleagues' experiences and gave me insight into why they were advocating so strongly for certain things. We were introduced to new ways of thinking about conflicting values, which was enlightening. We learned that respect for an individual may sometimes involve setting reasonable limits so the individual is not harmed. For example, family members smoking in the home posed an unacceptable risk for a patient on oxygen and would not be tolerated.

An interdisciplinary team meeting was held with the patient, her family, the inpatient hospice team, the home hospice team, and the ethicists. In this meeting, we set clear boundaries and expectations with the patient and her family. This helped our team feel more in control of a chaotic, unpredictable, and emotionally intense situation. It added consistency and clarified what the patient and

family could expect from our team and what our team would not provide for them. This unified our team and helped us recognize the importance of all team members providing a similar level of support for her based on the expectations we set. At the recommendation of the ethicists, clear expectations were set in relation to patient and family financial and legal matters being outside the scope of hospice support. Our teams recommended contacting a lawyer about these matters.

On the ethicist's recommendations, we started conducting visits in pairs with two hospice team members seeing the patient for each visit in the hospital and at home. We enhanced our documentation in the electronic medical record so clarity about what had been discussed and expectations that had been set were available to every hospice team member. We also set up a brief conference call with the home hospice and inpatient hospice teams every time she transitioned from one setting to the other. This provided opportunities to better understand her current needs from an interdisciplinary perspective, ask questions about her care, identify any new expectations that had been set, and check in with each other.

I'm struck by the healing power of an ethics consultation and its long-lasting positive effect on our team. The many challenging situations we had to navigate drove our team apart initially and caused ongoing conflict. As we cared for the patient over several months, team members sometimes became hypo- or hyper-engaged in the face of helplessness, as discussed by Dr. Anthony Back in an article in the *Journal of Palliative Medicine* (2015), which further challenged team dynamics. With help from the ethics consult service, our teams were able to come together to develop a consistent plan of care for the patient at home and in the hospital with clear plans for times she transitioned from one setting to another. I think about how the ethicists positively impacted the care of this patient and our entire team, including our ability to work together effectively toward a common goal and creatively problem-solve together.

Several years after caring for this patient, it's remarkable to me that I continue to work side by



side and have a deep respect for members of her care team. I often think about how different these working relationships would have been without the ethicists who guided us. Instead of this experience driving a wedge between team members, it brought us together, and we learned that we could navigate challenging experiences together as a team. I appreciated the ethicist's ability to teach us about the overriding ethical values and how to mitigate the impact of the values at risk. This experience helped team members identify their personal values and helped us learn about each other's values so we could work together more effectively. It's amazing to me that ethicists can come to a situation in which deep suffering and helplessness feel inescapable and can relieve suffering by sharing new ways of thinking, empathy, knowledge, and insight. I'm forever grateful for the healing power of the ethics consultants who partnered with our team.



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

Tracy R. Wilson

I am a doctorally-prepared nurse practitioner with over 20 years in healthcare, and I am currently pursuing my MS in Bioethics and Medical Humanities at Tulane University, with an anticipated graduation of May 2023. In the fall of 2022, I had the pleasure of taking a Clinical Ethics course. As part of that course, I shadowed a Clinical Ethicist for a week. It was a valuable experience, and I gained some insights about a role I didn't know about previously. The last two years have been difficult for my family and me. I lost my dad in November 2020 and then a "sister cousin" in May 2021. In both instances, we had the team involved in their care and helping with the decision-making process.

The role of the Clinical Ethicist Consultant (CEC) service is to help families process medical

decisions—most of those decisions deal with end-of-life care. The CEC works as the mediator between the family and the medical team. This is how I saw the CEC role play out in my experience.

During my shadowing experience, my preceptor was phenomenal at his role because 1) he listened to the patient and the family, and 2) he consulted with the appropriate team members. My shadowing experience was virtual due to the restrictions of the healthcare facility. However, I was able to attend ethical team meetings. I was able to listen to multiple family calls and consultations. During my experience, my clinical ethicist was very conscientious of taking inventory of the feelings of everyone involved. Before he provided an opinion on a case, he did a deep dive into the patient's chart to gain the patient's historical context. He always asked for my opinion while we discussed a case, which made me feel included even as a student. It made me feel like my opinion had some weight, and it did in one of the cases. When I returned the next day, the feelings I had about a patient and her family using her for financial gain turned out to be true. Elder abuse was taking place.

My personal experiences were more complicated, in which we didn't always have a medical team that always heard what we needed for our loved ones. In the case of my sister cousin, she entered the hospital and was diagnosed with COVID-19. Our family never thought she would die from it, so it was shocking to us when she was placed on a ventilator and never came off. When the critical care MD stated that "there was nothing else he could do for her," I could not understand how that could be when lung transplants were being done all over the US and even less than 100 miles away.

We needed a CEC team then. I was the medical expert for my family, and I felt the medical team was not listening to what we wanted. The medical team believed that to continue treatment would be futile and their belief about this exceeded their need to continue treating my sister cousin. However, having a CEC mediate by first understanding the clinical team's perspective, explaining those considerations to us, and then helping our family relay back our

wants, needs, and values to the clinical team could have helped. Unfortunately, my cousin never got this option. There was a palliative care team implemented but never a Clinical Ethicist. Having faced both, from a student perspective and from a personal experience, I would say that having a CEC present allows a family to have an advocate in the room, someone who knows the medical language and can explain to you and will explain to the medical team your perspective, which can sometimes be lost in translation or not heard.

When my father passed away, he did not have a Clinical Ethicist as a part of his medical team either. My dad was a Vietnam Vet and a very prideful man. So, when my dad became ill in 2018 with vascular dementia, it took a toll on me and my sisters. To see this towering man that was always full of strength begin to waver was almost too much for us. My father was eventually placed in a long-term care facility and was doing well. My father would call us regularly and check on us. My sisters would check on him on a weekly basis. Then COVID hit, and no one could visit. My dad was a social butterfly. When no one could visit him anymore, he stopped talking. After two weeks of no visitation, my dad's vascular dementia worsened. Despite the lead nurse setting up Zoom in the room for us, my dad never talked again. Six months later, my dad passed away. During his transition, we had a palliative care nurse who helped us decide to go with hospice care. However, we never got access to a CEC during his care. I'm not sure if it was due to a lack of resources or no one asking if we wanted access. If a family asks for help and someone explains properly what an ethics consultant can provide, I think most families would take advantage of CEC services, especially if they feel like they are not being heard by the medical team. There were moments early on in his illness we could have used their help, but we somehow managed to overcome the disagreement.

Watching how the CEC service worked in my shadow experience after my personal losses has given me a different perspective on the role. Every healthcare facility should have a CEC service, or someone trained in ethical principles. I believe every patient admitted to the hospital with certain

illnesses (heart or brain conditions, cancer, etc.) or as a trauma patient should get a consult or their family members or proxy decision-makers should get an introduction to the CEC team. The clinical ethicist can help the patient and family navigate the healthcare system more seamlessly.



### **“It’s All Personal”**

Frances Rieth Maynard

I was (am?) the mother of a full-term infant born in 1998 with hypoplastic left heart syndrome. This was my 3rd pregnancy; I had two prior pregnancies resulting in healthy children. Until that final week before birth, my pregnancy had been uneventful; my blood pressure, weight gain, and lab work charted normally. At my prenatal check (with a new physician as mine was away), my measurements were off. That OB-GYN referred me to a perinatologist who was able to perform an ultrasound (checking for infant size) and advised that I should deliver soon because the infant was markedly growth retarded. I was induced two days later. My small daughter was born with skeletal leg deformities and brought to the neonatal intensive care unit (NICU). I was familiar with that NICU since I had worked there as an RN prior to this pregnancy. I was comfortable with the environment, the people, and the overall culture of the place. Indeed, I had been a pediatric nurse for the previous 10 years working primarily in intensive care.

After my daughter's birth, I was able to intuit meaning by the placement of her bassinet in the unit (e.g., it was not too close to the nurse's station; she had no oxygen or tubing, and she was not in a private room). I believed that her journey home would be longer than I had planned but that it would occur. On that first day, a pediatric cardiologist arrived to perform an ultrasound. I was familiar with this scene too; I did not view this process as anything more than routine. I was relieved to have

a physician who I knew and trusted to watch over my daughter. This allowed me to go back to my room to rest as I do not believe I had slept well (if at all) after being informed there was a potential problem a few days earlier.

Less than two hours after returning to my room, my daughter had been intubated and begun on prostaglandins as the echocardiogram had revealed a hypoplastic left heart defect. The neonatologist started to discuss options for transport so my daughter could be treated at a larger hospital. I tried to catch my breath and process what I was being told. We spoke by phone with my husband who quickly deferred all decision-making responsibility to me because I was “the person with the medical expertise.” My thoughts raced with all these unforeseen circumstances, yet time seemed to slow down. I requested that an evaluation be made of other potential conditions before transfer since my daughter was also small for gestational age, something we had learned less than a week earlier, and she had some skeletal defects, an issue of which we were unaware until after she was born.

A head ultrasound revealed an absent corpus callosum, the region of the brain that connects the two cerebral hemispheres and allows them to communicate by sending and receiving signals from each other.

Given all the enormous medical issues my daughter was facing, I asked for her ventilator to be withdrawn and my husband concurred. We wanted our daughter to be baptized and to die a “natural death.” Our neonatologist indicated that our choices were reasonable. But, before the ETT could be withdrawn, I was advised that an ethics consult had been called by one of the nurses. I became angry, scared, and saddened at the thought of strangers (to me) deciding the fate of my daughter. The neonatologist told me not to be concerned, and I later learned that the ethics committee had “signed off” on the wishes of my husband and myself. My daughter was extubated and died 3 days later.

This happened 25 years ago. In retrospect, it is interesting to me that I began to distrust the nurses, wondering which one had called the consult. I could not understand how anyone could doubt that I, as a

mother, was not making the best possible decision, among bad alternative choices, for my daughter. I began to view the anonymous persons of the powerful ethics committee as a “them” who did not and could not understand my family.

I remembered, years earlier, working in the intensive care nursery where placards about Baby Doe regulations were posted. Suddenly, I felt as though my intentions were suspect and my own sense of vulnerability became overwhelming when I thought that someone else was determining my daughter’s future. Because the medical apparatus of which I had been a part had “failed” me, I lacked confidence in the system. The inadequate growth of my daughter had not been discovered in the prenatal visits that I faithfully attended; her heart defect was not picked up in the ultrasound two days prior to birth. I did not want an amorphous committee making the decisions that I believed were mine to make in the best interest of my daughter. I was someone who was comfortable assessing serious, life-altering issues in the professional space. I was not prepared for being relegated to being “on the other side.”

I have been contributing to ethics consultations as a healthcare provider for the past 10 years. Because of my personal experience, I always try to keep in mind the “us vs. them” feeling that I had when I was the focus of an ethics consultation and not the facilitator of one. That exposure to ethics consultation in my personal life has informed my professional understanding of contextual attributes in the process. For example, what I can appreciate now is that perhaps the nurses asking for consultation needed support for decisions being made about withdrawing treatment. I recognize now that whoever instigated, (note my pejorative verb), my ethics consult was not necessarily acting in a self-righteous way. Perhaps they wanted to ensure that all concerns were addressed. How is the prospect of ethics consultation made with families? In my own situation, I had interpreted the request by someone else as a barrier, as a hurdle that needed to be overcome, before achieving what I believed best. I had been told, to the best of my recollection, that we could not proceed with our desire for



extubation until someone else, someone who was not otherwise a part of this situation, could weigh in and make their recommendation.

How could the intention of ethics consultation have been communicated to me more clearly? If it had been voiced that other people also recognized that the significance of the circumstances warranted measured consideration, perhaps I might have felt part of a community of carers all looking out for the best interests of my daughter and her family. Or perhaps not.



## Fault Lines

Laura A. Katers

I first meet Shawn in person on the 46<sup>th</sup> day of his most recent hospitalization. We sit outside of a community hospital on a wooden bench dedicated as a place to “sit, pause, and reflect.” It’s a biting cold November afternoon and I try to keep my shivering at bay by thinking of warm things. Shawn is wearing only a thin hospital gown and socks, but the cold doesn’t seem to bother him. I’m his self-appointed chaperone so he can sit outside and vape.

“I hope you don’t think you’re doing me a favor,” he says. “I should be able to do this in my room.”

What Shawn doesn’t realize is that I’ve turned my day upside down for him and this vape. He is off balance and at high risk for falls and so he can’t leave his room without someone watching him. I yearned to do something *human* for Shawn and so I spent hours chasing for permission from his primary medical team. We etch out an agreement that just because I am offering to take Shawn outside, he shouldn’t expect the same from others.

Shawn is gaunt and toxic appearing, and visitors stare at us as they enter the hospital with one patron mouthing to me, “Are you alright?” as if I’m there against my will, but I see what they see. I watch as a stringy mess of brown hair falls away from

his upturned face; his eyes are closed against the sunlight. I’m overwhelmed by the odor of urine and feces and *staleness* because he refuses to let anyone help him bathe. We sit in an awkward silence initially, but nothing about Shawn is straightforward. After yet another prolonged hospital admission, he’s already made the clearest decision of his life. He’s 32 years old.

I learn that Shawn was diagnosed with Crohn’s disease, an inflammatory bowel disease (IBD), only two years prior. Such were the ravages of his illness and its lack of response to conventional medications and treatment modalities that he lost sight of himself, literally. His body morphed from strong and athletic to cachectic, his skin turned translucent. The first surgery after his diagnosis was an emergent one for a perforated bowel that nearly killed him and was rife with complications. Afterward, Shawn was frequently admitted to various hospitals with complex abdominal pain, followed by more surgeries.

This admission is different, however, because Shawn also has an abdominal infection so severe that it limits his ability to eat or drink. The nurses placed a peripherally inserted central catheter, or PICC line, which allows for intravenous delivery of nutrition and fluids, and he is made *terminally* NPO. *Nothing by mouth.*

Shawn’s abdominal infection also coincides with terrific pain that is never adequately alleviated. One night, out of a desperate attempt to momentarily escape his illness and reality, Shawn crushed the opioids he is given every few hours, mixed them with tap water, and injected them directly into his PICC line. He later admitted to doing this for *years* every time he had a PICC or IV access outside the hospital, which was often. Unbeknownst to him was that the nondigestible parts of the pills such as talc and cellulose—the bits that hold the pills together—end up in the veins as wells. These fragments travel to the lungs where they lodge in the alveoli and create an irreversible condition called “excipient lung disease,” leading to pulmonary hypertension, inflammation, and early mortality. Shawn had experienced increasing shortness of breath over the last year, and ground glass opacities on his chest

CT-imaging could reflect this rare phenomenon. Most notable, however, was how upset he became that no one warned him that injecting crushed pills into his PICC line could result in such damage.

“You see how desperate I’ve become,” he earnestly told his medical team. “Why wouldn’t you help me protect *myself*?”

From what I know, it’s evident that Shawn needs a PICC line to survive outside the hospital, yet because of his misuse of the line, it’s not recommended that he be discharged with one. Additionally, his primary care provider of many years is no longer comfortable prescribing him opioids due to safety concerns of either intentional or accidental overdose. Shawn is told repeatedly that additional surgery is the only logical option he has, and he learns about an experimental procedure in New York, but a positive outcome isn’t promised.

The addiction medicine team I work on was initially consulted to discuss available options for his complex pain management once discharged. We recommended Suboxone, a partial opioid agonist that is given sublingually so it doesn’t have to metabolize through the GI tract. Suboxone helps curtail opioid withdrawal symptoms, has mild analgesic properties, and because of its unique pharmacokinetics it also limits respiratory depression in the event of an opioid overdose, something called a “ceiling effect.” Essentially, Suboxone is the safest alternative for a patient with a history of misusing opioids. But perhaps even more than death, Shawn feared pain and he felt this medication wouldn’t be enough. As legal and ethical considerations began to outline what could be done, if anything, to safely manage his pain, fluid intake, and nutrition outside of the hospital, Shawn abruptly opted for hospice and demanded to be discharged. No PICC line. No opioids.

\* \* \*

The dilemma sat in my chest like a stone. When I think of ethics, I think of impossible cases with no clear answers and Shawn’s case certainly fit those criteria. How could a young patient with an otherwise treatable condition—but not curable, and not cancer—choose death? Could his family fight his wishes? Additionally, it didn’t seem right or fair

to take opioids away from a patient who needed them—was in fact tolerant and dependent on them—to function daily, and then preach abstinence.

Shawn’s case was the first time I was involved in a clinical ethics discussion not as a student or observer, but as a clinician with input to give. The ethics team facilitated the ensuing care conference where Shawn’s rights to leave, even amidst protests from his family, were outlined. Having trained in addiction medicine, I understood how the neurochemical changes of prolonged substance use or misuse, trauma, and complex pain can cause a person to do something they normally wouldn’t—how each of these phenomena alone and certainly all three together can *change* a person—and that this is not something that is prioritized in medical training, or even well understood in ethics. Shawn couldn’t change the fact that he’d injected opioids intravenously for years and so he felt his last hope was that he might have adequate pain management with hospice. He acknowledged that once his IV antibiotics were stopped—due to the lack of a PICC line—he would die within a matter of weeks, maybe less. But this was the choice he *wanted* and made.

After Shawn was discharged from the hospital, the ethics team continued to hold space to further explore and share our collective moral distress surrounding this young patient and his family, and our addiction medicine was invited in on more consultations. I learned how ethical discussions allow for many individuals from different specialties and backgrounds, inclusive of family and loved ones, to come together in ultimate support of a person’s wishes. For the first time, I also 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.

\* \* \*

As I sit outside with Shawn on the 46<sup>th</sup> day of his admission, I feel the paradox of offering to take him outside and *allowing* him to vape, as if he is a child having to ask a teacher to go to the bathroom. He is right, I’m not doing him a favor. But my goal is to offer him a window back to his personhood, not his patient status, and perhaps create an opportunity for connection. No comments. No fixing. No tests

or medical implications. After a while, Shawn does share, nudging open the door slightly into his dark world where he is shocked at how his suffering and life feel reduced to rules and checkboxes that are disconnected from what he believes he deserves. He ponders how the rules he's followed since childhood, that were meant to protect and make sense of things, suddenly changed and now he feels more like a villain than a victim of a terrible disease.

"I'm making decisions that no one else can, or must, make," he offers, tucking his shoulder length hair behind his ears, his face in full view for the first time. "And I need a break from all this." He sweeps his slender arms across our view of fall foliage and the meager hospital grounds. His hospital gown falls from his shoulders to his elbows and with the movement and I see the clear outline of his ribs, yet he doesn't shiver once in the frigid air.

\* \* \*

Last I heard, Shawn survived through the winter to the warmth of spring into summer and eventually graduated from hospice. He found a palliative care provider to manage his pain and, miraculously, can eat again. Although he still has a long way to go and is quite fragile, he's seriously considering the experimental surgery that just might extend the quality, and maybe even the duration, of his life.



## Difficult, Difficult, Lemon, Difficult

Maggie Taylor

I like to joke that my husband is a lemon—he suffers from manufacturing defects that prevent his body from functioning as intended. Illnesses other 40-somethings recover from quickly are things that land him in the hospital for weeks on end. So, it was no surprise last year that an epileptic seizure led to aspiration pneumonia, admission to the ICU, intubation, multisystem organ failure, and a Helivac ride to a regional hospital for a higher level of care. I was told that his odds of survival were about fifty-fifty. At the time, I was training as

a clinical ethics fellow, still relatively inexperienced but savvy enough to guess the true likelihood was probably lower. Doctors don't usually like telling brutal truths to families.

But the moral complexities of his treatment did not arise when he was on the verge of death. They came days later when he was getting better. He'd survived a major surgery, come off pressors, recovered from an acute kidney injury, did well on spontaneous breathing trials (SBTs), and tolerated sedation weaning. Ironically, this was the hardest part of the hospitalization for me. Some people tolerate endotracheal tubes. Others don't. My husband is in the latter group. He'd even self-extubated on a prior hospitalization. This time, he was too weak to lift his arms. Instead of pulling at the tube taped to his face, he stared up at me with wild eyes that said *I don't know what's happening but I hate it; make it stop.*

As his discomfort became more apparent, I pressed the intensivist, Dr. Roja<sup>1</sup>, about extubating. "He's alert, following commands, and hit the benchmarks on his vent settings."

Dr. Roja responded by saying she didn't feel my husband was ready. They would continue conducting SBTs and reevaluate the next day.

She said the same thing the next day.

And the next day. Then she suggested a trach evaluation. I rejected Dr. Roja's proposed compromise. Forcefully.

It wasn't just that I had trouble seeing my husband in this state of confusion and discomfort, although I did. I also knew continued vent dependence was something he would not accept. Over the course of our relationship, we've talked a lot about what interventions my husband would tolerate under various circumstances. This makes sense, given my profession and his health problems. He doesn't want to live no matter the costs, but only if he can do so without being a burden on those he loves or dependent on machinery long-term—which, for him, means a few weeks.

This is what I told Dr. Roja. At least, this is what I think I told her. It's doubtful I stated my reasoning

<sup>1</sup> The author uses a pseudonym to refer to the intensivist.

half that clearly, given my emotional, physical, and cognitive state. It had been two weeks since my husband was admitted, and I was depleted. I was living in a hotel across from the hospital, wasn't eating, and had fallen back into the vice of smoking cigarettes. Exhaustion and stress had made me combative: I had to defend my husband against this doctor who refused to do the right thing and take the tube out.

In what felt like a last-ditch effort to get me off her back, Dr. Roja suggested an ethics consult. It was embarrassing that the intensivist was the one to suggest ethics involvement. Consumed as I was by my job as my husband's advocate, I had forgotten my *actual* job.

The team was able to put together a family meeting within hours. Beforehand, the ethicist came to my husband's room and introduced herself to me and my mother.

"I work in ethics too, as a clinical ethics fellow," I said.

She responded: "Oh."

That was all. Not even a word, but a sound. I don't know what response I wanted, but that wasn't it. This made me suspicious of the process.

My mother and I joined the ethicist, Dr. Roja, and a palliative care physician in the family room. Dr. Roja led with a summary of my husband's clinical condition—it was improving but could decompensate again—and she presented her reasoning for hesitating to extubate. Dr. Roja felt that extubating conflicted with clinical goals that could be realized—namely, my husband not dying.

"Do you really think this is going to be a terminal extubation?" I asked. It didn't sound like it would be from the clinical update moments before.

The doctor's response was wishy-washy: "I think your husband can recover."

I tried to explain that not dying is one goal, but there are others that are equally valid: not wanting to be on mechanical support long-term, not wanting to be a burden to one's family, and not wanting to receive unnecessary treatment. I gave my reasoning—either he was getting better and could tolerate being off the vent, in which case he should be extubated, or he was not getting better and he would not accept remaining on the vent, in which

case he should be extubated. If push came to shove, he wouldn't want to stay on a vent indefinitely, whether it was through a tube or a trach, regardless of his clinical prognosis.

In response, Dr. Roja said all the right things, over and over again repeating that "What I care most about is what your husband would want." This drove me mad. I was telling her what he would have wanted. I told her I was there representing his preferences, that we had discussed scenarios like this, and that I was a practicing ethicist and knew what I was talking about.

None of it seemed to land. What Dr. Roja was really fixated on had nothing to do with my husband's wishes. She revealed it in another phrase she said repeatedly, "I don't want to have to reintubate him."

Those two sentences, and the insistence that my husband could recover, summed up the intensivist's position. I don't recall what the palliative care doctor said. To this day, I am not sure why he was there.

I do recall the ethicist's contribution. She asked whether once extubated, I would want my husband re-intubated. This was, to me, a nonsense question. A hypothetical that had no bearing on the decision at hand.

"I don't know yet. I'll have to see how he does off the vent."

The team hemmed and hawed at this. But without knowing how he would tolerate breathing on his own, it was impossible for me to say whether reintubation would be appropriate. Would it be indicated for airway protection or respiratory failure? Would there be other significant clinical changes? Would prospective reintubation be five minutes after extubating or five days? Would my husband have the chance to talk about what was happening or the ability to appreciate it?

I raised these questions and noted that in the scenario we were actually in, we knew everything we needed to know. He'd been intubated for what felt like a million years. (In reality, it was 11 days). His respiratory status had improved, his vent settings were minimal, and he was passing his SBTs. Continued vent dependence was incompatible with what I knew of my husband's preferences. And it was my decision to refuse treatment on his behalf.

But nobody was listening to me. The more they didn't listen, the angrier I became. My mother backed me up, delivering the same message in softer, less combative terms. This went on for nearly two hours. It didn't make a difference. The team wasn't budging.

But neither was I. I gave them a deadline: *Someone* needed to extubate my husband within 24 hours. I would deal with the question of reintubation if and when it was clinically indicated and not before. I felt powerless in the face of the team's stonewalling, and imposing a deadline was a way of taking some of that power back.

Having accepted that they could not kick the can down the road much longer, the team agreed to explore transferring my husband back to the first hospital he was admitted to, where the attending might be more open to extubating. They would also ask my husband what he wanted.

We all shuffled back to the bedside. It somehow fell to me to ask my husband whether he wanted the tube taken out. He nodded yes, as we all knew he would. But we all also knew he lacked capacity, and this was a meaningless exercise meant to give the illusion of respecting his preferences without actually having to do so. The whole consult was an act of theater.

The ethicist hung back after the doctors left. I thought she might take this as an opportunity to do something—anything—to address the moral concerns I was raising.

But no. What she said was, "We are missing the last page of your husband's advance directive. Do you have it with you?"

To be clear, nothing the ethicist said or did at this point would have made me happy. But this question was procedural, technocratic. It didn't reflect any understanding of the reasoning behind my request to extubate, an appreciation for my husband's values or his suffering, or an understanding that this had nothing to do with code status. And the last page of the advance directive dealt with terminal conditions, which he did not have. It would have been the last straw, but I'd run out of straws days ago.

"It was on his bed when he was transferred. If it was so important, you shouldn't have lost it!" I

snapped. I turned my attention back to my husband, and she left the room without another word.

Thankfully, this story has a happy ending. My husband was transferred back to the initial hospital and extubated without incident, breathing on room air and passing a swallow test within an hour. He ultimately made a full recovery. Actually, he's healthier than ever before.

His improved health makes revisiting this experience even more surreal. I have presented this story in several venues and discussed it with dozens of other professionals in the field of bioethics. Each time, I feel a bit differently about it: What was the point of the consult? What is the important lesson I learned? Was the consult successful? And I don't have a neat and tidy answer.

Looking back, I know what the intensivist was thinking: *This guy is young and not terminal and on a positive course—I'm not extubating him now.* I don't think she ever cared about what my husband wanted. But she really cared about giving him the best chance at recovering. She believed she was fulfilling her obligations. I believed I was fulfilling mine. And we found the only sliver of common ground between them. Is that the point of an ethics consultation? Maybe in theory, but that wasn't my experience of it.

The wife in me was so upset by my husband's distress that I appreciated some aspects of a solution-oriented consult, but was maddened that my intimate knowledge of my husband's wishes was not taken seriously. The ethicist in me is troubled by the lack of an interpretive voice or respectful consideration of the moral experience. Mostly, it worries me that a few questions about code status seemed to be the extent of this hospital's understanding of an ethics consult.

The human in me knows I'm incapable of assessing this in an unbiased way, and that my now-fading memory has distorted this story as much as my emotions have. The silver lining is that discussing my husband's "case" in professional contexts has helped me overcome the trauma of the experience—not only the experience of the consult, but the entirety of watching my husband come to the brink of death and then claw his way back to the living.



## Commentary

# Understanding Clinical Ethics Consultation: What Stories Reveal

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**Abstract.** This commentary reflects on twelve stories of participants in clinical ethics consultations from the perspective of family members, some of whom are ethics consultants, and healthcare professionals. Together they reveal expectations of ethics consultations and suggest descriptions of the service. Some common themes emerge, including the role of the clinical ethics consultant in navigating complex situations, assuring all stakeholder voices are heard, attending to moral distress, addressing issues that seem beyond medical practice, and being accessible. They are almost uniformly positive about the experience, with criticism primarily about lack of access to the service.

**Keywords.** Clinical Ethics Consultation, Ethics Consultant, Core Competencies, Moral Distress, Narratives

“**M**y co-residents, attending physician, and I were all aware of the implications this decision would hold, and at that time, we knew that an urgent ethics consult was needed to help guide us.” Austin Morris writes about the help he felt he needed as he and his team confronted a decision regarding code status and intensity of treatment for a 25-year-old patient. The patient had previously refused aggressive interventions, but once incapacitated, his mother requested treatment, stating that with more knowledge, the patient would have changed his mind. How would an “urgent ethics consult” be helpful in such a circumstance? Why is this a role for a clinical ethics consultant? Underlying these questions is the more basic question: What is clinical ethics consultation

(CEC)? This question, a regular topic in published literature, conference debate, and professional society discussions, has been variously addressed in the field of bioethics and now by these 12 stories. Since 1992, institutions accredited by The Joint Commission (TJC) have been required to have a process that allows patients, families and healthcare team members to address ethical issues or conflicts, a “mechanism to consider ethical issues in patient care” (The Joint Commission on Accreditation of Healthcare Organizations, 1992). This standard, however, does not mandate a particular process, provide quality measures, or detail function. The Society for Health and Human Values and the Society for Bioethics Consultation formed a task force to define CEC and explore standards. They published

a consensus document on core competencies in 1998 describing the components of CEC and competence in its practice. The successor organization, the American Society for Bioethics and Humanities (ASBH), produced a 2<sup>nd</sup> edition, published in 2011, and work on a 3<sup>rd</sup> edition is underway (American Society for Bioethics & Humanities, 2011). ASBH founded the HealthCare Ethics Consultation Certification Commission (HCEC Commission) in 2017, which created a certification process for clinical ethics consultants, allowing practitioners to formally demonstrate a baseline of competence in the major domains of the core competencies, including assessment, analysis, process, and evaluation.

Generally, the literature and consensus documents suggest that CEC is an advisory service available to assist patients, their loved ones, and healthcare professionals with identifying, analyzing, and resolving ethical issues, including questions, conflicts, uncertainties, and dilemmas. The process, whether provided by an individual consultant, a team, or a committee, is designed to recognize the perspectives of all relevant stakeholders to a patient's situation, to promote practices consistent with ethical norms, and to provide a moral space for addressing ethical issues.

These dozen stories from participants in ethics consultations suggest different descriptions and purposes, and interestingly, this is true even among the three participant authors who self-reported as current or aspiring bioethicists. Among these varying descriptions, there are some common themes, including the role of the clinical ethics consultant in providing guidance, assuring all voices are heard, addressing more than the ethical issue in attending to moral distress, and being accessible. The authors share an appreciation for this service, including those who were unable to access it or were unhappy with the consult that was provided, and a sense that ethics consultation provides something beyond medical practice.

### **Defining the Role of the Clinical Ethics Consultant: Navigation**

A common thread through these stories was a sense that clinical ethics consultation helped stakeholders

involved with a case navigate through complex, difficult, and uncertain medical situations, or as Laura Katers writes, "When I think of ethics, I think of impossible cases with no clear answers . . .". Michelle Prong specifically writes, "The clinical ethicist can help the patient and family navigate the healthcare system more seamlessly." Eve Makoff suggests consultation is useful when something has gotten "stuck" or "a reframe" is needed to address the uncertainty in medical practice. Jean Wilson describes the role of the clinical ethics consultant as a "mediator between the family and the medical team," there "to help families process medical decisions," again suggesting a role as a guide in the decision-making process.

One story suggested something more like patient advocacy: "Having a CEC present allows a family to have an advocate in the room, someone who knows the medical language and can explain to you and will explain to the medical team your perspective, which can sometimes be lost in translation or not heard" (Wilson). Despite the use of the term "advocate," a description often resisted by practicing clinical ethics consultants in their quest to provide neutral facilitation, it seems more appropriate to consider the consultant as a translator, an interpreter for the overwhelming medical terminology that seems unavoidable in family meetings with healthcare professionals. This again underscores the role a consultant may play in providing guidance or navigating the unfamiliar.

Though not defined as an explicit competency by the HCEC Commission, skills related to case assessment and process are suggestive of this role. This navigator metaphor reflects a shared sense of the role of the clinical ethics consultant, a neutral party helping all stakeholders traverse new, complex, or difficult terrain—gathering relevant information, identifying contrary perspectives, determining the ethical questions or concerns to be addressed. The role in navigation applies not only to working through challenging situations toward resolution, but also to the emotional turmoil the process may create. Prong explains, "Despite the complexity of the . . . case, the clinical ethics consult service helped us clear the path forward for the patient, at least in the short term."

## Assuring All Voices Are Heard

Another significant common theme is the clinical ethics consultant's role in including all stakeholders in a case, which is a skill explicitly included in the *Core Competencies*. In one story, the authors simply shared, "... we didn't feel alone . . . we felt heard" (Lisa P and Kerwin). In another story, Wilson, a nurse practitioner pursuing a MS in bioethics, contrasted her personal experience in which the medical team appeared not to hear what her family wanted, with the consultant she was shadowing, who was "conscientious of taking inventory of the feeling of everyone involved." Katers elaborates on this, "I learned how ethical discussions allow for many individuals from different specialties and backgrounds, inclusive of family and loved ones, to come together in ultimate support of a person's wishes. For the first time, I also 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." Lisa P and Kerwin go further, stating that the consultant, "in a sense, protected our opinions and beliefs on this decision, even though the doctors were very adamant that he should not do this and that he *could not even* do this . . . We were relieved that someone was listening to my husband's wish and rationale . . .".

Not feeling heard was an important theme in complaints associated with both the need for CEC and concerns about CEC. While Wilson felt her family was denied a clinical ethics consultant, someone likely to have heard her family's wishes, Maynard suggests that the ethicist did not acknowledge her voice. Though the ethics consultation supported her treatment preferences, Maynard expressed concern that her family was not consulted directly. She explains that she was "advised an ethics consult had been called by one of the nurses. I became angry, scared, and saddened at the thought of strangers (to me) deciding the fate of my daughter. The neonatologist told me not to be concerned, and I later learned that the ethics committee had 'signed off' on the wishes of my husband and myself." This resulted in a sense of distrust with the team, both of the nurses, "wondering which one had called the

consult" as well as the ethics consultant. Maynard continues, "I began to view the anonymous persons of the powerful ethics committee as a 'them' who did not and could not understand my family . . . an amorphous committee making decisions that I believed were mine to make." Because the consultant did not speak with her, she felt "relegated to being 'on the other side.'"

Similarly, Taylor, describes the consult as "technocratic," and states, "The whole consult was an act of theater." She felt the ethics consultant did not understand, or even seek to understand the situation or the family's preferences and values. She notes, "We found the only sliver of common ground. . . . Is that the point of ethics consultation? Maybe in theory, but that wasn't my experience." Brent Carr also expressed disappointment with the consultation process when the consult team met with the patient's family but not the team members. Carr acknowledges that the consult team had done what had been asked of them and that this made the team feel more "comfortable" with the decision that had been made. However, to him, it felt as if the consultation was "paternalistic" and "perfunctory." He had greater expectations of the service provided. While there is a lot to unpack in the descriptions of the consultation processes related to the assumptions about the nature of consultation requests, the power of the committee, and the goals of consultation, what is clear is the importance of the clinical ethics consultant in hearing and bringing all relevant voices to the discussion. Of note, this is an explicit skill required of clinical ethics consultants seeking certification.

## Moral Distress

Another shared theme highlights the role of the clinical ethics consultant in addressing moral distress. Laura Hoeksema, a hospice physician, describes a patient case in which, "Moral distress was running rampant," noting multiple sources of that distress, including the patient's situation, the time spent on the patient's care, the degree of autonomous decision-making the patient was allowed, and "passionate" beliefs about right and wrong. To address this, she explains that the ethics



consultants helped “draw out sources of moral distress . . . helped us clarify our individual values as we reflected on which of our values we felt were being disregarded or infringed upon.” Further, the consultants “affirmed that we were doing a good job.” In empathizing with the team members, they “helped us gain some perspective in the swirling tornado of our emotions.” Hoeksema credits the positive outcome, “Instead of this experience driving a wedge between team members, it brought us together, and we learned that we could navigate challenging experiences together as a team.” Prong echoes this sense, noting that the ethics consultant helped “empower team members experiencing moral distress.”

That role in managing healthcare professional moral distress does not end at the hospital door or with a patient’s discharge. As a healthcare professional, Katers noted that even after discharge, “the ethics team continued to hold space to further explore and share our collective moral distress . . .”

Increasing reports of burnout and rates of suicide among physicians and other healthcare professionals attest to an ongoing need to address moral distress in healthcare. Various wellness programs, debriefings, and forums focusing on emotions have been created to allow healthcare professionals to share their feelings and support one another. Some academic medical centers have developed formal moral distress consult services to identify sources of distress and strategies for improving it (for example, Hamric & Epstein, 2017). More often, however, it may become the role of the clinical ethics consultant to recognize and support healthcare professionals experiencing such distress. Ethics consultation itself may provide what Margaret Urban Walker called “moral spaces,” the time and space for healthcare professionals to reflect on and discuss the values and ethical beliefs that affect patients and the goals of care (Walker, 1993). Walker argued that ethics consultants are the “architects” of such spaces, both designing and maintaining them. In this way, the clinical ethics consultant is responsible for the content of the consult and the process of ethical decision making, rather than any decisions that are made. The *Core Competencies*

describe this facilitative role as a primary function of clinical ethics consultants.

## Beyond Medicine

“In some cases, what truly constitutes the best standard of care is uncertain, and oftentimes, we find ourselves stepping out of medicine into the world of medical ethics (Morris). In describing the story of the 25-year-old about whom life or death decisions would be made, the young physician telling his story shares his angst over the conflict between the patient’s previously expressed treatment preferences and the desires of that patient’s mother to save the patient’s life. He shares his sense of urgency and belief that such decisions are somehow beyond medicine. He expresses appreciation for their timely guidance, the ethicist’s role as a liaison between the team and the family, and assistance navigating difficult discussions, though he ultimately found that the recommendation “was not easy for me to accept.”

Jean Watson similarly suggests that the provision of guidance in ethically challenging situations is extra-medicine. “Prior to my hospital employing an ethicist, there was no standard approach, no guidance for these decisions, and no support to the providers and care team.” In describing working with a clinical ethics consultant to support decision making for an incapacitated patient without a surrogate decision-maker, she appreciates the consultant’s knowledge and skills, in the absence of an authoritative hospital policy, to handle challenging circumstances. She suggests such circumstances are “rare.” While the number of unrepresented patients encountered may vary among hospitals, it seems an inherent and regular part of the practice of medicine to discern individual values, assess medical opportunities, and reconcile differences between them to determine the best outcome for each patient.

Medical decisions frequently address the limits of medicine. Medical education focuses on the goals of cure, extending life, and preventing premature death. When the path to those goals is unlikely, unclear, or fraught, it may feel the decisions required are beyond the scope of clinical

practice. But even the Hippocratic Oath suggests that medicine is more, the obligation to comfort when healing is not possible, to be present for the patient, and to place the patient's needs over one's own. Healthcare professionals regularly encounter and assist with determining an individual's goals of care, have hard discussions when treatment is no longer possible or is disproportionately harmful, and work through the labyrinth of the healthcare system. Are these discussions to be left to the clinical ethicist, and if so, why is this not fundamentally what medicine is about? The role of the ethicist is to provide recommendations consistent with ethical norms and practices and ensure all perspectives are represented, but that decision-making remains the purview of the patient, their family, and healthcare team members. The original core competencies task force warned against the certification of individual clinical ethics consultants, "certification increases the risk for displacing providers and patients as the primary moral decision makers at the bedside because it gives the impression that certified individuals have special standing in ethical decision making" (Aulisio et al., 2000). Clinical ethics consultants may have the skills and time to provide support, but these processes remain fundamental to medicine.

Healthcare practitioners and scholars since Hippocratic times have described medicine as an inherently moral enterprise, guided by moral norms and codes of ethics. With every patient, questions about what should be done—and what treatment ought to be recommended—provide insight beyond what can be done or offered. Though not always recognized as such, these are fundamentally ethical questions. Ethical decisions and medical decisions have been described as inseparable (Jonsen et al., 1982). It is a moral infrastructure that supports the physician-patient relationship and the practice of shared decision-making. There is, or perhaps should be, an expectation that healthcare professionals be able to distinguish between what *can* be done and what *should* be done, to help their patients and families make difficult decisions. When the difficult borders on the impossible, shared decision-making process breaks down, conflict seems intractable, or

there are no clear answers, clinical ethics becomes a resource for addressing those ethical issues inherent to medicine that seem beyond easily accessible answers. In describing the tragic healthcare experience of her husband, Lisa P. recognizes this extension of the medical decision making processes. "At the time of the call to Ethics, we had no idea what 'Ethics' was, . . . we would never have known to call 'Ethics' if the palliative doctor had not advised us to do so, and my husband might have suffered a longer, more painful life" (Lisa P. and Kerwin).

### Access to Clinical Ethics Consultation

The stories collectively reflect positively on ethics consultation, with the most substantial critiques focusing on a lack of access. When the Joint Commission required hospitals to have a mechanism for addressing ethical issues in providing patient care, it recommended a multidisciplinary ethics committee (The Joint Commission on Accreditation of Healthcare Organizations, 1992). Though this requirement was briefly removed in 2023, it was reinstated and revised to require that a hospital "develops and implements a process that allows staff, [patients], and families to address ethical issues or issues prone to conflict" (The Joint Commission, 2023). While retaining the standard that mandates a process, there are still no specifics regarding what that process should look like, who should be involved, how the process is accessed, or any outcomes of whatever process is used.

In his story about providing ECT to a troubled patient, Carr describes an ethics consultation that supported the healthcare team's treatment plan as being helpful in overcoming divisions among that team, though he was not satisfied with the process. He then describes another case in which he recommended an ethics consultation. Though the ethics consult service agreed that the consult was appropriate, it never occurred because the attending physician did not feel one was needed. Carr suggests that "The initiation of the ethics consult may be an underestimated barrier." This he, contends, is because physicians are "unfamiliar" with what the service can offer, or perceive it to be "reserved for

catastrophic or high-profile cases,” or that it reveals a “deficiency in [healthcare professionals’] ability to manage ethical dilemmas” (Carr). Similarly, an anonymous author, self-reporting to be a trained bioethicist and the son of the subject of his story, expresses frustration with an attending physician who would not consult ethics believing the concern to be a medical question rather than an ethical issue. In both cases, access to ethics consultation was impeded by the attending physician.

Patients and their families often are unaware that CEC is available, as are many healthcare professionals. Though Carr had recommended ethics consultation, and describes it as readily available and well defined, he acknowledges that before encountering this complex and divisive case, he had never used the service. Wilson also complains about a lack of access, uncertain “if it was due to a lack of resources or no one asking if we wanted access.” Though unable to access the service herself, she believes that “most families would take advantage of CEC services, especially if they feel like they are not being heard by the medical team.” She does not indicate that she requested such assistance, but rather waited to be provided with access. Lisa P and Kerwin suggest that “there should be more ethics consultants involved in the care of patients and families who are struggling with difficult decisions in all healthcare settings,” and also “recommend that more patients and families should be made aware of the service.” Some hospitals do advertise the service, with public-facing websites, posted phone numbers, and embedded clinical ethics consultants, but often these services may be limited or obscured. Even those who are in the know may have difficulty with access like the anonymous author, or may not seek the service themselves, as Taylor was embarrassed to admit.

Professional norms have developed regarding the provision of ethics consultation. Ethics consultation is generally to be available to all stakeholders in a case, and not subject to administrative or physician consent, yet there are no regulations to assure this. The anonymous author, a bioethicist himself, was unable to access a consult, as no contact information was available, the hospital operator

was unable to assure a return call, and the attending physician thwarted the consult request. His every effort was stymied, and he was left with no recourse for the conflict he experienced. He offers lessons about ethics consult availability, clinician fallibility, and market forces, and suggests that there is no economic incentive to make ethics consultation services more accessible. To be compliant with the Joint Commission standards, it seems merely enough to have a service, whether or not that service is truly available, accessible or effective. The moral space may exist but behind walls.

## Conclusion

The stories suggest a very human understanding of clinical ethics consultation. None of the authors spoke of ethical principles, balancing competing values, or methods of reasoning. Rather there was appreciation relational aspects, particularly a sense of being heard, finding common ground, assistance with navigating the complexities of healthcare, and simply getting help that may or may not have been recognized as a need. The stories touch on other themes, not addressed here, such as the boundaries of clinical ethics expertise (versus law) (Prong) and compromise (Morris, Lisa P. and Kerwin), that would further describe the practice of CEC, as well as the distinction between personal and professional identities (Taylor).

In defining what CEC is, these authors focus on the process or the “how” assistance was provided as much as the actual guidance that was provided, or the “what.” The outcomes were clearly important, yet it seems it was not enough to get to concrete answers unless there was also an opportunity to participate in getting those answers. Clinical ethics reflects the intrinsic moral nature of medicine, which is fundamentally about the relationship between patient and healthcare professional. Clinical ethics consultants’ real role then is to provide processes for accounting for that reality, affording all involved the opportunity to determine right and wrong, good or bad, better or worse, in real human interactions that occur in the context of one of the most vulnerable of human states. These stories are

a testament to why and how to do that, and the value of the endeavor.

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## Commentary

# Three Types of Stories About Encountering Bioethics

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**Abstract.** This commentary discusses 12 stories about receiving ethics consultation in hospitals. Five stories are by physicians, three by nurses, and four by family members; three of the writers have training in bioethics. Some writers requested the consultation, others experienced the consultation as an imposition forced upon them, and in two cases, the story is about the absence of any consultation service. Three types of narrative are found to structure the stories: the genuine dilemma narrative, the institutional intransigence narrative, and the relational care narrative. Throughout, the question is what makes for a valuable consultation, and the general answer is whether consultation enables the development of mutually supportive relationships.

**Keywords:** Narrative Bioethics, Ethics Consultations, Fear in Healthcare, Hospital Dysfunction, Healing

One way to begin to think about what these stories of bioethics consultation teach us is to ask what is notable in their mode of narration. Twelve stories is not a great number, but it's enough that certain common features lead us to ask why the authors are telling their stories in the particular ways they are. I begin with what the stories omit—what is noticeably absent.

Curiously to me, although these stories are about bioethics consultations, the ethicists themselves remain shadowy presences. The most vivid characters in the stories—the characters I find myself visualizing or whose tones of voice I imagine hearing—are the narrators themselves, then the patients on whom the consultation focuses, and in several stories, the attending physician, who is often presented as an antagonist. Among the non-human actors that

affect the plot, hospital regulations and routines are significant: these include the staff rotation schedule in Michelle Prong's story and regulations on visiting during Covid in Anonymous One's story.

In some stories—Anonymous One and Tracey Wilson—there is no ethics consultant, and the story hinges on the absence of a consultation service. But even in stories that praise the value of ethics consultation, not enough is said about the ethicist for me to imagine an actual person, at least in anything like the way that Brent Carr allows, even forces, me to see the patient suffering from debilitating depression, or Laura Katers brings me into the presence of Shawn: his unwashed hair, how he smells, his indifference to the cold. By contrast, we are not even told basic professional information about the ethics consultants, such as the training



they have received. I would especially like to know what proportion of different consultants' time is allocated to ethics. In workshops I have given for frontline ethics consultants, participants often introduced themselves with a decimal, as in, "I'm .3 ethics." The authors are either unaware that such information about the ethicists might be relevant, or they do not feel entitled to ask, or perhaps they are too stressed to care.

These features of the narrations lead to what I at first found frustrating in the stories, but then realized might be what we should learn about the effect of ethics consultation. The consultations themselves are glossed over in generalities; in most stories, the consultation gets only a few lines of description. Lisa P, who finds great value in the ethics consultation, is the most candid about her lack of recall: "The resolution is foggy in my mind because it was such a difficult time." I read that not as a flaw in the narration, but as an evocation of the experience that included the consultation. Lisa P is telling how she experienced what happened during her husband's hospitalization: the fogginess is her experience; it's what the story is about, at least in part. All these stories are about how "ethics" is the work of helping people make critical decisions while in conditions of fogginess, as well as the need for ethics to lead professional staff to recognize how the institutional conditions of treatment play no small part in inducing the fogginess that frustrates the ideal of rational decision-making held by some versions of bioethics.

Eve Makoff's story is an exception to this lack of detail about the actual consultation. She alone gives the consultant a name, Dr. F, and she quotes him asking a specific question: "Tell me about your mother." In this collection of stories, that question has to work hard as a stand-in for other questions that authors imply in generalities but do not specify. It's a question I will return to below.

What the stories omit is significant but difficult to interpret: does the writer attribute less importance to what is omitted, or do they not remember, and is the reason for that an important part of the story?

Against this background of the stories' silences, I can recognize three general types of narratives.

I will call these the genuine dilemma narrative, the institutional intransigence narrative, and the relational care narrative. These types overlap, with some stories drawing upon two as their narrative resources. The types tell us a good deal about what families and healthcare professionals each want from ethics consultation, and the limits hospitals often impose on those consultations.

### **Genuine Dilemma Narratives**

Genuine dilemma narratives are told by medical professionals, mostly physicians. These narratives begin with the problem that Austin Morris articulates: "In some cases, what truly constitutes the best standard of care is uncertain." Among the genuine dilemma narratives, Brent Carr's story stands out. Carr's dilemma is that the best chance for mitigating the patient's horrific suffering is to administer ECT, but the patient's heart condition poses a significant risk of death from ECT. That kind of dilemma makes a classic bioethics case study, with experts weighing in on both sides.

But what the consult produces is not the sort of expert opinion that a bioethics journal would publish. Carr describes the consultation as "perfunctory," yet either despite that or maybe because of it, the consultation is successful in aligning the medical team with a course of action. "Oddly," Carr writes, using a word worth taking seriously, "all team members now verbalized how comfortable they were with proceeding with ECT." He offers one reasonable explanation: "Did the consult mitigate angst by diffusing ownership of a potentially bad outcome?"

Carr's disappointment at the lack of engagement "in an ethical debate" seems to me to be only the tip of an iceberg, that being a dysfunctional lack of honest discussion in the unit. "The nursing staff voiced their frustration," he writes; "Medical students confidentially articulated their confusion and concern to only the resident but were apprehensive about expressing their thoughts at the team level." The problem seems not so much a lack of ethical debate, which sounds a bit academic. The problem is a work environment in

which people feel unable to express their deepest ethical concerns.

What I would like to imagine a well-facilitated discussion of ethics producing in the team or unit is a willingness to talk and keep talking about the impossible choices that clinicians sometimes have to make, and the suffering of living with those choices. Ethics consultation might help clinicians find ways to mutually support each other in making these impossible choices—support that will matter crucially when things go badly, which in this story means the real possibility of ECT killing the patient. Again, institutional process is a crucial non-human actor: in this story, what combination of factors lead to the medical students finding it threatening to express their thoughts at a team level?

If the objective of an ethics consultation on a genuine dilemma is merely the productivity goal that the wheels of treatment grind on—which seems to be the case in Carr’s story—then the consultation does its job. But if “ethics” is about creating a working environment that offers mutual support, and if that support, in turn, requires free expression of personal reservations and doubts, then Carr’s disappointment with the consultation reflects a deeper malaise in the institutional conditions of practice.

### **Institutional Intransigence Stories**

If professionals tend to tell stories that fit the genuine dilemma narrative (e.g., Morris, Carr, Prong, Hoeksema), family members tend to tell institutional intransigence stories. That intransigence is, of course, from their perspective. What matters to me is not who has better reasons for acting as they do, but rather the inability of professionals, including ethics consultants, to recognize why families find the institution intransigent and to explain the institution’s position, if such an explanation has any credibility. If not, then the consultant should acknowledge that, which seems to be what happens in Lisa P’s story.

Lisa P faces the intransigence of physicians who installed her husband’s LVAD but now refuse to de-activate it. Anonymous One faces intransigence over Covid visiting rules—an issue that

the attending physician refuses to categorize as “ethical.” Frances Rieth Maynard experiences a requirement for ethics consultation as an institutional barrier to carrying out her clear wishes for her daughter’s care. “I became angry, scared, and saddened at the thought of strangers (to me) deciding the fate of my daughter,” she writes. It does not seem that the ethics consultant took time to anticipate how this mother would predictably feel this way, or that the consultant saw it as their role to allay that justifiable anger and fear. In too many of these stories, the crucial issue of how people *feel* does not seem to be on the ethics consultant’s agenda.

Maggie Taylor expresses the toll that her adversarial relationship with her husband’s physician had on her: “. . . I was depleted. I was living in a hotel across from the hospital, wasn’t eating, and had fallen into the vice of smoking cigarettes. Exhaustion and stress had made me combative: I had to defend my husband against this doctor who refused to do the right thing and take the tube out.” The response of the ethics consultant after spending some time with Taylor, is one of the most appalling moments in all these stories: “What she said was, ‘We are missing the last page of your husband’s advance directive. Do you have it with you?’”

This failure to recognize and give proper acknowledgement to Taylor’s suffering and to how the hospital contributed to that suffering is, for me, the ethical point of this story. Taylor experiences the tick-box ethics that Carr describes: the ethics opinion being rendered “as though it were a solitary lab order that had returned a simple, concrete value.” However such work might serve institutions, to call it “ethics” is shameful.

### **Relational Care Narratives**

A third type of narrative offers a view of what ethics can be as the facilitation of relationships of caring. Lisa P’s story begins as an institutional intransigence narrative and then morphs into a relational care narrative. The words *relational care* should be redundant: how could care not involve a relation between persons? But stories like Taylor’s show that

in contemporary hospitals, what institutions count as care often excludes any quality of relationship.

Lisa P shows us what a relationship actually requires. The ethicist answers questions, which is what we would expect; she helps to “navigate,” which is also expected but clearly does not happen in some other stories. Then Lisa P describes the ethicist as “not afraid,” which is an unexpected observation: fear is not often a topic in bioethics. Reading that, I realize how much fear there is in most of these stories, and how ethics consultation papers over that fear and by repressing it, arguably makes it more toxic.

Carr is explicit about medical students’ fears of speaking out about their concerns. Maynard and Taylor are explicit about their fears of their loved ones being held hostage to unending medical interventions. But I also ask how much fear is felt by the physicians who are the antagonists in stories by Anonymous One, Maynard, and Taylor: what are these physicians afraid of, or maybe better said, what are the layers of their fears, including peer judgment, institutional position, and legal liability? Can the ethicist be the one *who refuses to be afraid*, in an environment saturated with intersecting fears? Can the ethicist make fear a topic of the consultation, thus enabling speech that has been repressed?

Lisa P’s relationship with the ethicist continues when that person is present with the family when the LVAD is de-activated, a gesture of support that is rare among professionals. Even rarer is the ethicist then staying in touch. “We are still in touch today, five years from that date, and I do not think any other hospital service remains ‘with you’ consistently throughout the course of such a traumatic and complex journey.” As in other stories, Lisa P does not tell us specifics of what was said, but maybe the specifics matter less than being present. The ethicist shows up, embodies what the cliché “fully present” represents, and keeps on showing up. Here especially, I would love to know more about how this ethicist’s institutional position is defined; what supports the ethicist so she can support families?

What caring through relationship building means in practice is equally evident in Laura Katers’s evocation of her relationship with Shawn:

“After a while, Shawn does share, nudging open the door slightly into his dark world where he is shocked at how his suffering and life feel reduced to rules and checkboxes that are disconnected from what he believes he deserves.” Relational care is sitting with Shawn in the cold; staying with him through his initial hostility, acknowledging that he still opens a door only “slightly,” and not being afraid that the world inside the door is dark. Katers evokes the opposite end of a continuum from the tick-box ethics described by Carr: “all the necessary legal obligations had been met, the established lack of capacity had been appropriately documented, attempts to ‘avoid harm’ were present, and affirmed husband was legally able to consent.” Reduction to those tick marks is exactly what Shawn experiences: it’s his fear and his desperation.

### Lessons Learned

So many lessons can be drawn from these stories. The following seem most important to me.

First, genuine dilemmas bring to the surface the underlying dysfunction of too many healthcare work environments. Some of this dysfunction is structural, such as the frequent staff rotations that fracture the continuity of ethical care in Prong’s story, a story that trails off at the end as she herself rotates off that service. Other dysfunctions are more difficult to label, because they are multiple in both causes and effects. Anonymous One’s story is a dramatic example: the ethics consultation service is structured so that Dr. Stewart can decide unilaterally not to allow a consultation. All the institutional intransigence stories show such structural dysfunctions, although what counts as dysfunction from a family perspective, or from an ethics perspective, counts as efficiency from an administrative point of view.

Reading this collection of stories, I was left believing that ethics consultation readily focuses too narrowly on particular patients and clinical dilemmas, often ignoring the institutional dysfunctions that compound individual and family suffering. That dysfunction includes the unspoken suffering of healthcare providers that is glossed as “moral

distress” in these stories’ descriptions of teams. But ethicists are usually hospital employees, and hospitals do not pay employees to generate demands for reform of how work is organized. For the consulting ethicist, that is a foundational dilemma.

Second and addressing institutional and professional dysfunction, when ethics consultation does heal, it does so by enabling things to be said that either there was no time for, or perhaps speaking how one feels is actively suppressed. To find what I would call healing, I go back to Dr. F’s simple question in Makoff’s story: “Tell me about your mother.” What Makoff describes as the ripple effect of that question is, to me, worth calling a miracle: “The daughter was now able to connect who her mother was with what she would want in this moment. It was as though by gathering us together, passing our worlds alongside theirs, we created a community of caring and attention.”

That community is what Carr hopes that ethics consultation will bring about, but it doesn’t. We do see and hear such a community in Laura Hoeksema’s description of how ethics consultation healed the structural rift of two care teams with different concepts of the patient’s needs and welfare. “We came to understand that because of the values we hold so dearly and prioritize differently, we had divergent perspectives on her care.” Hoeksema describes team members as becoming “hypo- or hyper-engaged in the face of helplessness.” That description resonates throughout all these stories. I understand the most intransigent characters in these stories as being, at the same time, both hypo- and hyper-engaged. That duality is paralyzing; it renders these people incapable of entering relationships that require listening, incapable of openness to alternative perspectives, and incapable of willingness to change.

Third, if after reading these stories, I ask myself what is this activity, commitment, or capacity called “ethics”? I return to Hoeksema’s phrase, “in the face of helplessness.” Ethics is enabling people, who include healthcare professionals, family members, and ill people cast into the restrictive role of patients, to get past the fear of helplessness and find ways to act. That action involves risk, whether that

is the risk of someone dying or being kept alive in situations when death would be preferable. Because most actions will not end happily—the happy ending of Taylor’s story being a welcome but rare exception—ethics needs to help people discover different conceptions of what counts as a good ending.

As an ideal of the effect that bioethics consultation might engender, I quote the poet Christian Wiman (2023), who has lived for years with cancer. He writes about the double effect that Shakespeare’s *King Lear* can have on audiences: “Even stranger, perhaps, that one can walk out of a good production of *Lear*—which is *definitely* an expression of despair—both stricken and enlivened, numbed and newly alert. . . .” (Loc 666). After reading these stories, the double effect that Wiman describes does not seem that strange. Anyone who is truly cared for in ethics consultations, as the more fortunate among the narrators of these stories are, might emerge both stricken and enlivened, numbed and newly alert. That certainly is the effect I feel reading these stories.

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## Commentary

# Clinical Ethics Consultations: What do Requestors Say?

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**Abstract.** This symposium collection of twelve narratives from individuals who experienced clinical ethics consultations provides perspectives from a group that has not been adequately explored in the bioethics literature. The authors represent a variety of stakeholders who received ethics consultations: healthcare providers and family members. This commentary will focus on three themes addressed in the different narrative accounts: the reasons for requesting an ethics consultation; the expectations of the narrators from the consultation; and the conclusions the authors drew from their experience of the ethics consultation.

**Keywords.** Bioethics, Decision-making, Ethics Consultation, Experiencing Ethics Consultation, Healthcare Workers, Narrative Ethics

## Clinical Ethics Consultations: What do Requestors Say?

The field of clinical ethics has seen rapid growth in the last decade, with increased efforts geared towards professionalization and developing competence standards. While clinical ethics consultations have been found to be effective in decreasing the length of stay in the intensive care unit (ICU) and increasing family and healthcare provider satisfaction in the critical care setting (Au et al., 2018), most ethics consultations are typically requested by healthcare providers and rarely by patients and families (Marathe et al, 2022). A recent study of ethics consultations at 600 US hospitals demonstrated that in 56% of the hospitals surveyed, ethics consultations are never requested

by patients or families (Fox et al., 2022). This symposium collection of twelve narratives from individuals who requested clinical ethics consultations provides perspectives from a group that has not been adequately explored in the bioethics literature. The authors represent a variety of stakeholders who received ethics consultations: attending physicians, physicians in training, nurses, family members who were lay members of the public, family members who were clinical ethicists, and family members who were students or trainees in the clinical ethics field. This commentary will focus on three themes addressed in the different narrative accounts: 1.) the reasons for requesting an ethics consultation, 2.) the expectations of the narrators from the consultation, and 3.) the conclusions the authors drew from their experience of the ethics consultation.



## Reasons for Requesting an Ethics Consultation

Ethics consultations are typically requested when there is a conflict of values, an ethical dilemma, or uncertainty (Wocial et al., 2016). The stories in this collection provide insights into the medical situations that triggered the ethics consultation request. Apart from the facts, though, what is also evident is the impact of those situations on the authors that prompted the consultation request. For the reader, these accounts paint a powerful picture of emotional distress and turmoil as they struggled with healthcare decisions that needed to be made.

In “Against Their Wishes: The Gift of a Good-bye,” resident physician Austin Morris recounts feeling “an urgent ethics consult was needed to help guide us” when confronted with the issue of following the wishes of a 25-year-old patient. Upon arriving at the hospital, the young patient expressed wanting to forgo resuscitation and intubation if it were needed to save his life. Later, the patient was diagnosed with liver failure and was considered for a liver transplant. Given the medical team’s discomfort with the situation and knowing that the patient would inevitably die without intubation and never be considered for transplantation, they wanted an ethics consultation as they seriously considered overriding the patient’s prior wishes and rediscussing code status with the patient’s mother.

In “Fault Lines,” Laura A. Kater describes a similar dilemma in which the providers struggled to accept a young person’s wish to choose death and request an ethics consultation to help guide them. These descriptions raise the question of whether the providers would have experienced similar discomfort and still felt the need for an ethics consultation if the patients were older individuals with the same clinical diagnosis and prognosis.

Along the theme of overriding patient wishes, Lisa P (the anonymous wife of a patient) and co-author Jeanne Kerwin describe calling for an ethics consultation at the recommendation of the palliative care physician. In “Lisa’s Story,” the physician recommended the ethics consult after Lisa’s husband was told that the cardiology team would not honor his request to deactivate his left ventricular assist

device (LVAD) since the device was working. The patient’s misery and continued suffering, coupled with not having his autonomous wishes followed, caused the provider to recognize an ethical issue. Meanwhile, the patient and his family remained unaware of how to label the issue they were experiencing or that hospital-based ethics resources were available to assist them with the situation.

Inequity in accessing the ethics consultation service arises as a theme in many family-based narratives in which the service appears to be well-known to hospital providers, but patients and families struggling with ethical dilemmas and uncertainties are unaware of the resources.

The inability to access the ethics consultation service is an issue that is brought up more acutely in several of the narratives. In the anonymously written paper, “My Father Dies Alone,” the author outlines his frustrations with not being able to request an ethics consultation when the physician and hospital refused to authorize family visitation for a patient at the end of life. Unlike the lay public, the writer, being an ethicist, could recognize the ethical issues but had no recourse to avail of the ethics consultation services despite multiple attempts to request their assistance.

## Expectations from Ethics Consultation

As the narratives relay patient stories and the reasons why an ethics consultation was requested, they also provide a window into the expectations of the requestors from the consult process or what the requestors hoped to accomplish as an outcome of that process. The expectations described in the provider narratives capture many of the common expectations from ethics consultation as described in the literature: Police, Equalizer, Superhero, Expediter, Healer, and Expert (Finder and Bartlett, 2022). Eve Makoff’s “The Clinical Ethics Consult: Transforming Ambivalence to Action” discusses calling an ethics consultation when “something has gotten stuck or could benefit from a reframe.” Makoff—a physician—applies this expectation to a difficult palliative care case amid personal ambivalence about her choice to switch medical specialties. We

also sense elements of expecting the ethics consult to protect the vulnerable and answer a list of complex questions in Laura Hoeksema's "The Healing Power of an Ethics Consult" when conflict between inpatient and outpatient hospice teams ensued. The teams struggled to keep a dying patient safe at home. The notion of the expert and the rescuer comes up in Michelle Prong's "Whose Voice Matters? The Role of Ethics Consultation in Supporting the 16-year old Healthcare Decision-maker of a Critically Ill Neonate." Brent Carr's "Side Stepping the Issues: Disappointment with an Ethics Consult for a Medically High-risk Patient" deals with unmet expectations of having a neutral party weigh in with their expertise regarding a difficult decision and also addresses mixed emotions around the patient care situation from different team members.

There is variety in the narratives when it comes to family accounts of their expectations. Expectations range from having none—"We did not know what to expect, but we called" from "Lisa's Story" and the anonymous writer of "My Father Dies Alone," desperately attempted to request an ethics consultation despite not articulating what they were expecting the ethics consultation service to do in their father's case.

In "Clinical Ethicists: Can They Help Families in Their Times of Need?" Tracy Wilson compares and contrasts her shadowing experience as a bioethics student observing the merits of an ethics consultation with her personal experience as a family member, where she felt an ethics consultation was needed when the medical team was not listening to what the family wanted. Having not received access to ethics consultation with her family members, she writes how the ethics consultation would have helped mediate between the medical team and understanding the family's values and wishes. In sharp contrast, Frances Ruth Maynard describes feeling "angry, scared, and saddened at the thought of strangers deciding the fate of my daughter" after being informed that an ethics consultation had been called given the parents' request to withdraw the ventilator and allow a natural death for their baby, born with hypoplastic left heart syndrome. Even though this event happened 25 years ago, the raw

emotion of the author's feelings are evident as she questioned how anyone could even imagine that she, as a mother, was not making the best decision for her child. Maynard talks about the committee and its members as a "them vs us" who could not appreciate the family's views.

Given her ethics fellowship training, Maggie Taylor shares feelings of embarrassment in "Difficult, Difficult, Lemon, Difficult," when the intensivist is the one who suggests ethics involvement for her husband. Continued conflict over Taylor's husband's care plan consumes her time and attention and causes Taylor to forget her "actual job." This juxtaposition of advocating for a family member while also looking at the situation from the lens of an ethicist comes alive in several of the family-based contributions.

## Experience of Ethics Consultation

Given the limited amount of work that has been done in the area of recipients of ethics consultations, the narratives capture the essence of ethics consultations, the tension between expectations and reality, as well as the enduring impact of the encounters on providers and families over a long period of time. The narratives are sufficiently compelling to note that the clinical situations involving requests for ethics consultations have left a moral residue over time such that the authors are able to delve so clearly and deeply into the emotions they were experiencing during the tough situations described. Providers of clinical ethics consultation can learn broadly about the impact of their work on individuals involved in consultation experience and improve their practice.

Jean Watson, in "Unbefriended," discusses the need for standardized policies to mitigate unconscious bias when making decisions for patients who lack a surrogate decision maker while describing how an ethics consultation experience provided "long-lasting friendship" for members of the hospital team that came together to make end of life decisions for such a patient. Along similar lines, Laura Hoeksema talks about the positive impact of the consultation on the whole team by bringing

providers with different values to effectively work together. Laura Katers considers the value of the ethics consultation from the perspective of inclusive decision-making, holding space for moral distress, and providing an avenue to advocate for patients with “challenging or misunderstood behaviors to have a louder voice in their care.” Reflecting on his disappointment with an ethics consultation, Brent Carr touches upon the barriers to engaging the ethics service, questioning the familiarity of physicians with what an ethics consultation could offer, the perception that the service is only available for “catastrophic or high-profile cases,” and the fear of “scrutiny” or suggestion of “deficiency to manage ethical dilemmas” if a physician requests help. Eva Makoff’s piece comments on the change in the practice of ethics consultation over the years with ethics consultants who are more “accessible” and “dug into the hard stuff right alongside us.” She shares how the consultation experience not only helped the patient care situation get “unstuck,” but it also helped her personally move forward with her career choice. In “Lisa’s Story,” the patient’s wife outlines how much her husband and she appreciated having the ethics consultation, especially in the context of not knowing what to expect. Not only were she and her husband comforted that someone was listening to the patient’s wishes and his rationale to discontinue the LVAD, but the ethicist also provided moral clarity for the patient that LVAD deactivation was not akin to committing suicide. The patient’s wife talks about how her husband would still be suffering if they had not received guidance to request an ethics consultation. Additionally, the continuity of care provided by the ethicist and their need to have a “constant resource to reassure” they were doing what was best for the patient helped them immensely, “we didn’t feel alone . . . we felt heard.” The narrative ends with a recommendation that more patients and families should be made aware of the service and that more ethics consultants should be involved in supportive decision-making for patients and families.

The theme of listening comes up again in Tracy Wilson’s narrative and her recommendation that “every healthcare facility should have a clinical

ethics consultation service” to “help the patient and family navigate the healthcare system more seamlessly.” The anonymous family-based narrative details the importance of availability and clear advertising of the ethics consultation service for patients and families. It notes that patients and families “should never be put in a position where an ethics consult must be routed through a person involved in the dispute.” Maggie Taylor’s story shares a deep disappointment with the ethics consultation experience when she perhaps needed it the most. Caring for a husband who was intubated but whose wishes were clearly known, the medical team and the family found it extremely challenging to reach common ground. Being a fellowship-trained ethicist, Taylor recalls the trauma of the entire experience, frustrated by the lack of an “interpretive voice or respectful consideration for the moral experience.” Frances Maynard considers the benefit of ethics services clearly communicating with families about the intention of its involvement.

## Conclusion

The narratives in this symposium provide powerful insights into the experience of receiving an ethics consultation. The accounts clearly outline the triggers of an ethics consultation, the expectation of request, and the lived experience of providers and families as they underwent the consultation. For clinical ethicists to be effective at their work, they need to be aware of the impact of their work on individuals seeking care and those providing care. The narratives provide a compelling reason to increase access and awareness amongst patients and families about the consultation service.

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