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“Amputate My Arm Please — I Don’t Want It Anymore”

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A STORY OF CINDY

All of the names and some of the details of this case have been changed or omitted to respect the privacy of those involved.

Cindy Johnson was 50 years old. While working on an assembly line 10 years ago, she injured her wrist. Since the injury, she suffered from complex regional pain syndrome (CRPS) in her left hand and forearm. CRPS is a neuropathic pain disorder that arises after painful trauma affects a limb.¹ A gentle breeze passing over Cindy’s exposed skin would cause excruciating pain and a burning sensation. She kept her forearm protected with an Ace bandage and a hard brace, often resting her arm on a pillow — a minor protection and visible sign to others to keep their distance. She needed a spinal block to endure the excruciating pain of dressing changes. As the block wore off, the pain would become unbearable. On the last admission, she returned to the emergency department shortly after a dressing change to receive a continuous infusion of levobupivacaine to anesthetize her arm. Her last dressing change was over a year ago. Due in part to suboptimal hygienic management that was inevitable with such infrequent dressing changes, she suffered from cellulitis and edema in her left hand and forearm. She also had joint contractures in her left hand, and her muscles atrophied from lack of use. Her arm was red and swollen. She took neurontin, percocet, trazodone, and methocarbamol to relieve pain and associated symptoms. Without more frequent dressing changes, her cellulitis would spread, causing ulcers and recurrent infection.

Cindy willingly received psychiatric treatment, because, as is often the case with CRPS, the severity of her pain did not correspond to the severity of the underlying injury.² She received counseling and took an antidepressant. Her decision-making capacity was intact and, except for minor depression, she had no other psychiatric issues. Despite Cindy’s faithful cooperation with psychiatric, palliative, and physical therapies, her pain continued.

Cindy lived with her husband and cared for her five-year-old grandson James. She was existentially and physically exhausted by constant pain and her inability to properly clean and protect her arm. Her in-patient team of physicians, including general medicine, psychiatry, the pain service, and anesthesia, presented treatment options. Treatment options included intrathecal opioids, a spinal cord stimulator, and dorsal rhizotomy (cutting the spinal nerve roots). She did not want the dorsal rhizotomy because it would cause her face to

droop, and she might experience numbness on her left side. She was not a candidate for a spinal cord stimulator because there were too many nerve endings in the area, and the contractures in her hand were a contraindication.

Cindy refused all proposed treatments and requested amputation. Her physicians warned that amputation would probably not alleviate the pain because phantom pain would be likely to continue.³ Cindy wanted amputation for hygienic and personal reasons. She would take the risk of phantom pain. Her arm was alien to her and negatively impacted the quality of her relationships, especially her relationship with her grandson, James. The child was always afraid that he would hurt Grandma.

The treating physicians repeatedly spoke with Cindy about treatment alternatives and the risks of amputation. Cindy consistently assured them that she understood that amputation was unlikely to alleviate her pain. While Cindy was certain, members of the team (including myself) remained uncertain about whether amputation was medically or ethically appropriate or beneficial. As we grappled with the ethical dimensions of the case, we asked ourselves the following questions. Was her capacity to make decisions compromised by desperation? Was amputation a reasonable elective treatment alternative? Did the harms outweigh the benefits for Cindy? If so, should surgeons refuse her requests for amputation? Whose perspective should take precedence — the medical team's or Cindy's?

MY MOTIVATION FOR INVOLVEMENT IN THE CASE

A formal ethics consultation was never called, hence, my role was not to help facilitate resolution of an ethical conflict, as it is in formal ethics consultation.⁴ The process of moral deliberation had begun among those who had most at stake. The deliberation was proceeding as one would expect — physicians were talking to one another, and the patient was trying to decide what was best.⁵ I learned about Cindy during my routine attendance at multidisciplinary rounds. By attending rounds, I try to offer assistance with emerging ethical issues before they become dilemmas and identify areas of ethical concern for resident physicians and other healthcare providers for discussion and education in various forums, both formal and informal. After talking with the resident physician after rounds, I asked the attending physician, Miriam Lam, MD, if she would mind if I talked with Cindy about her choice. Lam welcomed my involvement, as the treating team was divided about how best to proceed. Still, my involvement was unsolicited. So why did I involve myself in the case?

First, I want ethics consultation to be more proactive than reactive. By making this shift, we can focus on giving careproviders the skills to address ethical issues and spend our time supporting staff, patients, and families in their ethical deliberations. This strategy is better than sweeping in at the final hour when an avoidable dilemma has arisen. Hence, informal consultations are routine in my practice, but informal consultations usually do not involve visiting patients, since I am most often responding to careproviders' concerns about ethical dimensions of patient care.

Second, I want to help. Vulnerable patients call out for a special kind of attention and care, inspiring a desire to protect. I feel this desire strongly. While I am intellectually aware of the dangers, the sentiment remains. The desire to protect, especially in the role of a clinical ethics consultant, can lead to meddling and ineffective consultation. Rather than focusing on facilitating conflict resolution, excavating shared values, and collaboratively envisioning creative solutions, it is possible to become distracted by the drive of one's own conviction.

I visited Cindy before I reflected on the motivations just outlined. When I asked her if she would mind speaking with me, she was receptive, willingly telling her story and answering my questions. Cindy described a crisis of corporeal and personal integrity. She told me, "This arm just gets in the way. I'm sick of being careful with it and telling everyone else to watch out. I can't play with James for fear of bumping into him. If it's gone I won't worry about that anymore." She sometimes described it as "this arm," not "my arm." Her arm created dissonance in her relationships. When I asked her if her husband and children agreed with

amputation, she offered a knowing smile. She had been asked this question before. She said, "They wish I didn't have to do it, but they see how much I've been suffering. No one can assure me the other treatments will cure my pain either, at least not without side-effects I don't want to live with. It's a risk, but it's what I want. And my family supports me."

Cindy's vulnerability was different from the vulnerability I often see in my work. She was capable of making her own decisions. Any question of her decision-making capacity was motivated by her unusual request, not unclear thinking. She knew what she wanted, to the point that she proposed an unorthodox treatment plan. She was vulnerable because she was trapped in her own body and only a surgeon could "save" her. While clinicians worried that amputation was an elective disfigurement that would not alleviate her pain, Cindy thought of amputation as a liberation. Her arm had become alien to her, marked by a sustained disruption to her sense of self because of a disruption in the relationships that shape her.⁶ She experienced a crisis of corporeal integrity. She wanted to be free.

The third reason I became involved was because I was curious. The particular vulnerability Cindy displayed had intrigued me for some time.⁷ How do people learn to live with an illness or injury that forces them to change their very notion of themselves? Not only corporeal but personal integrity has been radically challenged, and the patients courageously find and recreate themselves. I admire them and want to hear their stories. While I have no problem asking patients to teach us, in Cindy's case I was inexcusably unaware of how my own curiosity and professional self-interest compelled my involvement. At the end of our conversation, I asked Cindy if I could tell her story, especially in my work teaching residents. She willingly agreed, and my interests once again prevailed. I believed at the time that my involvement was more about wanting to help, but there was a clear conflict of interest. At the time I did not see it.

Finally, I became involved because I wanted to assist the treating team in dealing with their moral distress. By report, Cindy sounded both desperate and absolutely convinced that amputation was best. Maybe by speaking with her I would better understand the paradox and quench my desire to help. We genuinely did not know what was best to do. We all wanted to be certain. Once again, I should not have been seduced by the comfort of certitude. I should have known better. The moral life entails living with uncertainty — doing what we think is best without the benefit of knowing if our actions will bring the good we desire. Ethicists collaborate with others to provide clarity in a complex situation, but striving for *clarity* does not mean striving for *certainty*. Maybe I confused the two.

MORAL DISTRESS AND PROFESSIONAL INTEGRITY

Moral distress is itself a kind of haunting. Moral distress arises when we identify the right course of action but feel constrained to act upon it.⁸ Likewise, moral *uncertainty* breeds moral distress. Moral uncertainty is marked by nebulous, negative feelings or "warning" intuitions that are experienced when individuals have not yet identified the source of their discomfort. Moral uncertainty can be addressed by gathering more information and by clarifying and naming the source of distress. In Cindy's case, our moral distress arose from moral uncertainty. Moral distress influences professional integrity because it is a visceral response to a conflict between our personal values and our professional obligations.⁹ If our primary obligation is to help patients restore the personal integrity that is jeopardized by illness and injury, then acceding to Cindy's request would be ethically warranted. But if Cindy's request for amputation conflicts with the professional or personal values of healthcare providers, then a challenge to professional integrity would arise.¹⁰ If we did not believe that amputation would be beneficial, should we have condoned it, even if Cindy believed it was her best option? Wouldn't this have compromised our own integrity? If we did not actively discourage amputation, would we have failed Cindy?

The attending physician, Miriam Lam, resolved her moral distress by talking with Cindy. Miriam said, "As I talked to healthcare providers and Cindy, I felt ambivalent. I wasn't sure what was best to do and this troubled me. Amputating an arm is irreversible! What if she changed her mind? What if her pain got worse?"

At first I wasn't sure what we should do. But that slowly changed. The more I talked with Cindy, the more I felt amputation was right for her. And I just accepted that it was my job as her doctor to do what was right for her, even if I didn't completely understand." Cindy's clear autonomous expression of her wish to amputate assured Miriam.

But not everyone was assured by Cindy's clear, consistent, autonomous request. Several surgeons refused to amputate, citing a conflict between obligations of nonmaleficence and beneficence. Some careproviders on the pain and psychiatric services also disagreed with the option of amputation. Caregivers may refuse to offer medically indicated procedures that conflict with their personal or professional values, provided another healthcare provider is willing to care for the patient, and they certainly did not need to offer treatments that were outside the standard of practice.¹¹ Amputation was not medically indicated for treating CRPS. The surgeons had no obligation to amputate, but *only* a surgeon could grant Cindy her wish.

After speaking with Cindy, I came to the same conclusion as Miriam. Cindy knew what she was doing and knew what was best for her. While individual surgeons refused to operate, I believed amputation was ethically permissible, given that Cindy understood the possible repercussions. Had I succumbed to the lure of a patient's informed autonomous request — the "autonomy trump card"? There were at least two ways to think about this dilemma. On the one hand, when a patient is capable of making decisions, we should trust her thoughtful assessment regarding harms and benefits when she suffers from a disability that negatively impacts the quality of her relationships. On the other hand, Cindy's physicians had an obligation to minimize harm or provide benefit, neither of which was expected by the careproviders in this case. At most, to perform the amputation would be a "zero-sum game," as it would leave Cindy in the same amount of pain, but without an arm. To this day, I think favoring Cindy's assessment of benefit over a more objective "medical benefit" was ethically justifiable, but reasonable people disagreed on this point, particularly when they believed that Cindy's pain compromised her decision-making capacity. I did not believe this was the case, especially because a psychiatric assessment had confirmed Cindy's decision-making capacity.

WHAT HAUNTS ME?

Ethics consultants, like their partners in consultation, experience moral distress and disequilibrium, as well as remarkable opportunities for moral and professional growth. Bliton and Finder wrote: "Faced with intense, specific, and explicit attention to the actual circumstances, to the genuine agony and potential disruption encountered by vulnerable patients and their loved ones, and by clinicians, the ethics consultant's own sensibilities and judgments may undergo a kind of *disequilibrium*."¹² Clinical ethics consultants experience disequilibrium when they encounter tragic cases; when, despite all efforts, tragedy and suffering prevail. In such cases, consultants often feel powerless. My involvement in Cindy's case represents a different kind of disequilibrium — the subtle haunting that arises from critical reflection and the belated acknowledgment that I could have done better.

First, I am haunted because, in retrospect, I see that my moral distress took center stage. I was so relieved when Cindy assured me that amputation was best for her. Her assurance was a gift. Cindy's conviction made amputation, an irreversible intervention unlikely to alleviate her chief complaint, ethically permissible. With that assurance, the case was closed for me and many members of the treating team. Was this the "respect for autonomy" trump card? Did I find it easier to agree with Cindy because doing so would relieve my moral distress? Cindy might truly be harmed by amputation. That reality did not change with my relief or her conviction. My distress arises not because I am haunted by the outcome, but because I see that the process was flawed.

Second, I am haunted by the fact that evidence suggests I did little to help. In fact, I might very well have contributed to Cindy's distress. Despite my attempts to be nonthreatening and to let her know that she did not have to speak with me, she probably perceived me as another institutional hurdle to clear before someone would grant her wish. She had to tell a painful story to yet another stranger. After living in pain for so long,

why should she have had to speak to an ethicist when her discussions with her doctors were genuinely ethically productive? Also, because there was no formal consult, I did not speak with all of the people who were struggling with the decision to amputate. If I had truly wanted to help my colleagues, I would have spoken with more of them.

Third, I failed to recognize clear conflicts of interest. I had almost nothing to lose and a lot to gain from talking with Cindy. I was curious and worried about her. She might quell my curiosity and address my uncertainty. My conversation with Cindy has benefited me professionally as well. I add a valuable teaching case to my repertoire. At the end of our pleasant conversation, in which we discussed both her values and the ethical concerns of the treating team, I asked Cindy if I could use her case for teaching. She agreed without hesitation. Even in retrospect, I do not think I exploited Cindy, but I was not as sensitive as I should have been. Was I trying to make myself useful to the medical team, blind to the price (however small) that Cindy would have to pay? Probably, as I was new to the institution at the time and wanted to make a good impression. I wanted to be an interested, collaborative, and proactive ethicist with a gentle and respectful demeanor.

OUTCOME

After several surgeons declined to amputate, one agreed to operate. Cindy did not experience any major complications from surgery, although, several years after her surgery, she continues to be treated for pain. How is Cindy doing now? Was amputation best for her? Does she regret it? How is her relationship with her grandson? I honestly do not know. I have not spoken with her since her hospitalization years ago. But later, when we admitted a patient with apotemnophilia, a condition in which an able-bodied person wants limb amputation for nonmedical reasons, I did not speak with him. I really wanted to, but I did not. Instead, a student who was working closely with the patient pulled me aside at multidisciplinary rounds, and we talked at length about the ethical dimensions and our professional responsibilities to a patient who was vulnerable but capable of making his own decisions. I offered to help if she, the patient, or team needed it. I think this informal consultation reflects an improved practice, because I was able to be proactive without unnecessarily interjecting myself into the therapeutic relationship.

NOTES

1. G. Wasner, M.M. Backonja, and R. Baron, "Traumatic Neuralgias: Complex Regional Pain Syndromes (Reflex Sympathetic Dystrophy and Causalgia): Clinical Characteristics, Pathophysiological Mechanisms and Therapy," *Neurologic Clinics* 16 (1998): 851-68; G. Wasner et al., "Complex Regional Pain Syndrome — Diagnostic, Mechanisms, CNS Involvement and Therapy," *Spinal Cord* 41 (2003): 61-75.

2. G. Vacariu, "Complex Regional Pain Syndrome," *Disability and Rehabilitation* 24, no. 8 (2002): 435-42; P.R. Wilson, "Complex Regional Pain Syndrome — Reflex Sympathetic Dystrophy," *Current Treatment Options in Neurology* 1 (1999): 466-72.

3. L. Siddle, "The Challenge and Management of Phantom Limb Pain after Amputation," *British Journal of Nursing* 13, no. 11 (2004): 664-7.

4. Society for Health and Human Values — Society for Bioethics Consultation, Task Force on Standards for Bioethics, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998).

5. D.M. Dudzinski, "The Practice of a Clinical Ethics Consultant," *Public Affairs Quarterly* 17, no. 2 (2003): 121-39.

6. E.D. Pellegrino and D.C. Thomasma, *The Virtues in Medical Practice* (Oxford, U.K.: Oxford University Press, 1993); R.M. Zaner, *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue* (Athens, Ohio: Ohio University Press, 1981); D.M. Dudzinski, "The Diving Bell Meets the Butterfly: Identity Lost and Remembered," *Theoretical Medicine* 22 (2001): 33-46.

7. Dudzinski, see note 6 above; D.M. Dudzinski and M. Sullivan, "When Agreeing with the Patient Is Not Enough: A Schizophrenic Woman Requests Pregnancy Termination," *General Hospital Psychiatry* 26 (2004): 475-80.

8. B.L. Tiedje, "Moral Distress in Perinatal Nursing," *Journal of Perinatal and Neonatal Nursing* 14, no. 2 (2000): 36-43; P. Hefferman and S. Heilig, "Giving Moral Distress a Voice: Ethical Concerns Among Neonatal Intensive Care Unit Personnel," *Cambridge Quarterly of Healthcare Ethics* 8 (1999): 173-8; D. Sundin-Huard and K. Fahy, "Moral Distress, Advocacy and Burnout: Theorising the Relationships," *International Journal of Nursing Practice* 5 (1999): 8-13; J.A. Erlen, "Moral Distress: A Pervasive Problem," *Orthopedic Nursing* 20, no. 2 (2001): 76-80.

9. J. Andre, *Bioethics as Practice* (Chapel Hill, N.C.: University of North Carolina Press, 2002); M. Benjamin, "Philosophical Integrity and Policy Development in Bioethics," *Journal of Medical Philosophy* 15, no. 4 (1990): 375-89.

10. Pellegrino and Thomasma, see note 6 above.

11. A.R. Jonsen, M. Siegler, and W.J. Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 4th ed. (New York: McGraw-Hill, 1998).

12. M.J. Bliton and S.G. Finder, "Traversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawal of Life Supports," *Theoretical Medicine* 23 (2002): 233-58.