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Real Life Informs Consent

Felicia Cohn

Felicia Cohn, PhD, is Director of Medical Ethics at the University of California, Irvine, School of Medicine, fcohn@uci.edu. ©2007 by *The Journal of Clinical Ethics*. All rights reserved.

My husband gripped the drawing of a human heart in his hand, trying to make sense of what the physician was saying. Our daughter, Amanda, had been born with a heart defect and the pediatric cardiologist had been talking with us for what felt like forever. The phrases “incompatible with life,” “surgically repairable,” “the next 24 hours are crucial,” hung heavily in the air. She was our first baby and had been whisked off to the neonatal intensive care unit moments after birth. When she did not return after the 30 minutes promised by the nurse, we knew something was wrong. The new daddy gazed at me without comprehension, wanting to understand what was happening and to make it right. The healthcare professional in me tried to explain, but the new mommy could only cry, choking on the words I wanted to get out. We had decisions to make — the life and death kind that no one should have to make — but all of my experience with similar situations did not prepare me for the emotion involved with being at the center of decision making myself.

By the time Amanda was born, I had been doing ethics consultations for more than a decade, had done research on end-of-life care, and regularly taught medical students and residents about informed consent. I was used to emotional situations, practiced at teasing out the factors relevant to making difficult decisions. I had the elements of informed consent well-rehearsed: capacity, voluntariness, disclosure, understanding, recommendations, consent, and authorization.¹ I regularly break them down for my students, role playing each one so that they can practice, preparing them to help their patients. The students fret over how much to disclose and how to get the signature on the form. They are concerned about legal protections and how much time they have to spend “consenting” a patient. These, however, turn out not to be the most important concerns.

My doctors did a good job. They recognized my capacity for decision making, despite the haze of sleep-deprivation from being in labor all night and the effect of post-partum hormones. My obstetrician, the cardiologist, the surgeon, and the ICU nurse spent time describing Amanda’s condition, her medical and surgical options, the benefits and downsides of each, the option of doing nothing, and their recommendations. My obstetrician knew me well enough to know what kind of support I needed and how directive he should be. To the credit of all, I didn’t even see an informed-consent form until just before the surgery, after much dialogue. The process truly had been conducted over time, an ongoing conversation over the hours available until urgency bordered on emergency. Yet even with the abundance of explanation and patience demonstrated by my healthcare professionals, none of it made sense.

As Annie Janvier notes in her article, “How Much Emotion Is Enough?” “Most big decisions in life are not purely rational, yet the cold legal concept of informed consent is.”² Emotion is an undervalued part of the informed-consent process. It, probably more than educational level, belief system, or socioeconomic status, affects our ability to understand the effect of the decisions we must make under difficult circumstances.

While my students worry about the concrete elements of informed consent, it is this less tangible lesson I now try to impart.

I was fortunate in Amanda's situation, if there can be a silver lining to such a tragic situation — years of evidence indicated the best treatment plan, and a surgical fix was possible. The disclosure was easy, not even too time-consuming, as was getting me to sign the form. But the decision making remained hard. I was being asked to make decisions while preoccupied with trying to make sense of a situation I did not want to comprehend. The "what ifs" were overwhelming. "What if the medicines don't sustain her until her first procedure?" "What if the procedure doesn't work?" "What if the surgery doesn't work?" "Is this the best place for this surgery?" "How will she live after the surgery?" And the unspeakable, "What if she dies?" The questions swirled in my head, but I was helpless to ask any of them. Every time I opened my mouth the tears welled up again. My questions went unasked, much less answered. Heart over head, all I could do was nod "yes," asking the doctors to save Amanda's life. In the end I did not care about any other implication of my decision. My decision was not rational, although it appeared so as it coincided with the physicians' proposed treatment. My understanding was assumed rather than established.

For years I have been frustrated by patients or patients' families asking that we "do everything" even in the most dire of circumstances. For the first time I truly came to understand the power of emotion in the decision-making process. While I had long taught my students that patients/families retain decision-making authority even if the decisions they make do not appear to be rational, it was rationality that I regularly sought in consults. The patient/family must demonstrate that they understand the consequences of the decisions they have made. I seek clear explanations for these decisions, believing that if the patient/family can explain it, they must understand it. We must "check" for understanding by asking the patient to explain the course of action selected in his/her own terms or through the questions the patient asks.

Yet the patient overwhelmed by emotion may not be able to do so. I could no sooner have translated my daughter's surgical plan into my own words than I could have performed the surgery myself. My husband, clearly the more coherent of the two of us at the time, struggled with the medical situation the doctors had explained. He is an intelligent, well-educated person, but lacked the background to understand the medical speak, and the willingness to accept the circumstances.

Consenting to the treatment proposed meant Amanda might live. To new parents nothing else mattered. I could not distance myself from the situation, as I do in clinical consults, to assess the facts. I cannot help but wonder if I would have been able to allow my baby to die, even if that would have been the more medically appropriate decision. The families of my patients may be similarly hamstrung, or guided, by emotion. Sometimes treatment, even if it is unlikely to be beneficial, is desired, despite the burdens, the likely futility, the expense. Other times refusing treatment, even when it is likely to prolong life and improve its quality, may perpetuate misery that cannot be explained logically, or at all. How we feel and what we want may govern the decision making of even those who should know better.

Our story has a happy ending: Amanda is now three, a healthy, active, and sweet little girl who wears her scar like a badge of honor. We are thankful for all that the physicians did, for the guidance they gave, for their efforts to help us understand. The book and drawings they gave us to describe Amanda's condition sit on a shelf in her bedroom, awaiting the day we need to more fully explain the scar on her chest to her. Now we understand and recognize that we made the best decision. Yet, as I look back on what happened, I am struck by the limits of informed consent. I knew my baby was fatally ill, but did not truly understand what that meant. I knew the surgery could save her life, but could not have explained how. I knew I wanted her to live, to come home, to grow up, and in light of that, all of the downsides to the treatment plan were invisible.

From experience, I have learned that the greatest constraints on informed consent lie in the requirements for capacity and understanding. These two elements are intimately tied together as the ability to understand essentially defines capacity. Illness impairs capacity in inconceivable ways. Yet the pursuit of rational decision making may blind physicians to what is really important about making hard decisions. And this, as Janvier implies, may mean that when rationality yields an undesirable answer, more effort to incorporate emotion is needed.

Of course this makes the physician's job even more difficult. There is no tool for measuring the appropriateness of an emotionally charged decision and emotional decisions often give rise to concerns about capacity, particularly when they are contrary to a physician's recommendations. However, we must recognize that sometimes the best decisions are neither rational nor even understandable to anyone other than the decision maker.

I still teach my students to ensure that their patients are able to make decisions and to understand the decisions they make. I share stories about lawsuits due primarily to assumptions about capacity, misunderstanding, or insufficient understanding. I emphasize the need for an ongoing conversation, for the disclosure of information appropriate to the particular patient rather than to the "reasonable" patient.

But now I also teach them that our most important decisions are often irrational (the very decision to have a child, for example) and that illness inherently compromises decision-making capacity. Our desires may trump even the most logical of plans. I teach my students to understand that their patients may not always understand and often do not behave rationally. Informed consent must be measured by empathy as well as rationality. This is both the burden and beauty of the human art of medicine. The practice of medicine allows for emotion in ways that law and policy cannot. Emotion may or may not save a patient's life, but it does give medicine a soul.

NOTES

1. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 4th ed. (New York: Oxford University Press, 1994), 142-81.

2. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE*.