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How Much Emotion Is Enough?

Annie Janvier

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Most big decisions in life are not purely rational, yet the cold legal concept of informed consent is. A patient should understand the nature of an intervention and what is likely to occur with or without it, should know about any possible alternatives and what they are, and should have the opportunity to ask questions.

When life-and-death decisions arise, emotions play a larger role as one's world starts to crumble. Physicians may typify decisions as irrational or rational, and may describe decisions with phrases such as "in denial," "too anxious to understand," or "taking time to digest the news," et cetera.

I am a neonatologist and am also a PhD student in bioethics. In 2005, for my second pregnancy, I delivered at 24 weeks and five days at the hospital where I work. My husband is also a neonatologist and is Chief of Neonatology at the same hospital; he is the master of evidence-based medicine and knows about every article published in neonatology.

What about *our* informed consent?

I presented to the delivery room at 23 weeks and three days, dilated at four centimeters and with bulging membranes. For those who are not in the field, this is not good news. In 1994, the Canadian Pediatric Society (CPS) and Society of Obstetricians and Gynecologists of Canada (SOGC) published "Management of the Woman with Threatened Birth of an Infant of Extremely Low Gestational Age."[1] At 23 to 24 weeks, prognosis was deemed so poor that life-saving interventions were considered optional. The AAP holds similar views,[2] as does the Nuffield Council on Bioethics.[3] Because of my background in bioethics, I was the one who wrote up the information sheet that our hospital gives to parents in these situations, to help them in making decisions. I know that sheet by heart.

My baby was in the "optional" category and we had to make the decision. Because I have an over-active imagination, I had already walked myself through this possible course of events in my mind, many times over.

Physicians like patients who are able to give consent, who can understand, and who can weigh two decisions, ask questions, and choose the best option for them. But when the alternatives are an uncertain life with an uncertain chance of handicap versus a certainty of death, the equation is difficult to solve: when your baby is dead, she is certainly dead; when she is handicapped, she is 100 percent handicapped. Is a rational, thoughtful decision really possible for any parent at such a time?

When a parent's decision "to do everything, at any cost" does not appear to be in the child's best interest, often comments are made that this has been caused by a problem in communication:

"If the physician had used non-medical terms. . . ."

"If the physician had stayed longer. . . ."

"The translator and the religious representative were not good. . . ."

"An ethicist, a philosopher, or a psychologist could have helped. . . ."

Even though these comments are true on occasion, sometimes death is not what parents have in mind for their child at a particular moment. Fear and love, emotions and desperation, are not rational.

In the delivery room, I said what I had decided many years ago: "Nothing before 24 weeks, and then we will think about it. At 24, maybe 24 and three. . . ."

The team was generally happy with our decision; it might have been different if I had told them to "do everything no matter what" at 23 weeks, or "do nothing no matter what" at 24 weeks. My baby had only good prognosis factors, she was a girl, I had prenatal steroids for more than 48 hours, she had a good weight, my husband and I have a good socioeconomic background.

When emotions are discussed in the informed-consent process, they are often thought to negatively influence competence. In an interesting article, "Is Mr. Spock Mentally Competent?", Louis C. Charland asks if the flight officer from *Star Trek,* who is part Vulcan and therefore unable to experience emotion, could make a truly informed decision.[4] In Charland's view, even if he is a "perfect cognizer," Mr. Spock does not represent an ideal of competence.

In delivery, I was a Mrs. Spock, a rational queen, and a great patient in terms of consent. My husband knew more of the medical literature, but he was the emotional one. My membranes ruptured before 24 weeks: in this situation, 50 percent of women deliver in 24 hours, 75 percent deliver in 48 hours, and the remaining 25 percent in an indefinite period . . . this is what I was thinking while my baby was moving, while I received my intramuscular medication, while the urine bag was changed, while my rectum was dis-impacted.

Even when one is maximally well informed, such decisions should not, in my mind, be approached only rationally — and cannot be. Most of the important decisions we make in life are not made in a cold-blooded, rational fashion: which partner to choose, whether to have children, where to work, and so on. We all have experiences, not only in medicine but also in our daily lives, in which unwanted information may not be heard, and this is not always "denial" or "wishful thinking." When we advise our best friend not to marry an *inconsiderate jerk* that she *knows has cheated on her many times,* and she *knows will do it again* . . . she may be intelligent, she understands what probably will happen, but she decides otherwise. Then again, my own decision to enter into a relationship with my partner was also irrational!

Our daughter Violette was born at 24 weeks and five days. The nurses and the physician told me "Congratulations," and I was livid. Would they congratulate a father who had dropped his baby on the floor? Why did they congratulate me for having a sloppy uterus? The guilt experienced with a premature delivery is paralyzing: "What if . . . ?" and "What could I have done?" become obsessive questions.

Violette had a rocky course. She became severely infected at one month of age, stopped passing urine, became comatose, and her blood pressure was not responsive to the maximal therapy. . . . My husband is an expert in blood pressure for neonates and ventilator management . . . so we knew the stats were not on our side.

On 14 June, after discussion with the treating team, we decided to withhold therapy, extubate Violette, and let her die. The statistics were no longer statistics, and the uncertainty would become certain. I just saw myself listening, saying yes, and felt like it was not happening, similar to the descriptions of women who were raped and were "not there." This decision was made by Mrs. Spock and her husband before visiting the unit to say goodbye.

My breasts hurt and I had to pump. I remembered, vividly, entering a parent's room and witnessing a mother pumping after her baby's death: she was crying almost at the same rate as the pump, squeezing her milk to throw it away, pumping for a dead baby. I thought this was one of the saddest images I had seen. Now it was me, pumping because of the pain. I tried to cry but I couldn't. It seemed the decision was the best one possible.

While we visited before the extubation, Violette started to slowly suck on her pacifier. My husband saw this as a sign: she was improving and there was hope. I answered, "Even anencephalics can suck: brain stem, brain stem!" He could not let go even if she was bloated, marbled, and pale!

I was angry that a knowledgable physician could interpret these details in such an irrational manner, after our baby's death was planned. I chose to listen to him because, if she was really in irreversible septic shock, she would not improve and he would change his mind, but I also knew that a period of prolonged low blood pressure is not good for future brain function. I also chose to listen to him because I love him, because we had to be on the same side, and because I couldn't fight for my daughter's death. Violette continued to improve, redeteriorated, improved again, and left the hospital four months after her birth.

Consent in serious decisions requires not only cognition, but also emotion. Uncertainty and emotions are what drives us, what tears us apart, what stimulates us, what makes us cry and sweat and laugh, but they can also kill. I suffered from hypoplastic emotion syndrome, and maybe wish I had felt more.

Some of our friends think my husband and I made a good decision because we are knowledgable; they think if only all parents were as well informed, they would all make good decisions. Others think we made a good decision because our daughter is alive and we are happy. None of these are true. Because the outcome was good does not mean the decision was made well. Retrospective analyses of consent when the outcome is known are simplistic: if there is a "miracle," a dubious decision becomes good and the doctors are heroes. On the other hand, when a patient does badly, many caregivers "knew it from the start." We "went too far," and the physician can be blamed for the lack of informed consent.

A woman who dies despite mastectomy, irradiation, and chemotherapy, experimental therapies and bone marrow transplant did not necessarily make a bad decision. We can never predict with certainty who will do well and who won't, and this does not imply you cannot adjust and "do well" if your child is not "normal." It is not rare to hear caregivers say "had we known this would happen, we would not make this decision again."

Violette is now two years old, and she has no serious disabilities. She still breathes fast and is myopic, and it is too early to know how she will do at school. She is a beautiful tiny little flower who is slowly growing (much too slowly!), surrounded by her scarred and thankful parents. We made a good decision because it is the one we made at the time. I made the decision fully informed, rationally, but with no emotion.

Emotion saved her life.

NOTES

1. "Management of the Woman with Threatened Birth of an Infant of Extremely Low Gestational Age," *Canadian Medical Association Journal* 151, no. 5 (1994): 547-51.

2. H. MacDonald, "Perinatal Care at the Threshold of Viability," *Pediatrics* 110, no. 5 (November 2002): 1024-7.

3. *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues* (London: Nuffield Council on Bioethics, 2006) *http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_8_November.pdf,* accessed 10 October 2007.

4. L.C. Charland, "Is Mr. Spock Mentally Competent? Competence to Consent and Emotion," *Philosophy, Psychiatry, & Psychology* 5, no. 1 (March 1998): 67-81.

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