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Let's Value, But Not Idealize, Emotions

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The courageous accounts by Annie Janvier¹ and Felicia Cohn² in this issue of *JCE* describe the most difficult decisions a parent could ever face and show how limited the prevalent model of rational deliberation is for "informed" decision making. For a parent, how can the death of a child be an option to be weighed and balanced against other options? As Janvier and Cohn so vividly describe, parents' raw emotions play a crucial role in registering the values that are at stake in such profoundly difficult situations. Thus, as Jason Higginson³ and David M. Browning and colleagues⁴ argue, emotions need to play a role within decision making itself, and a role that is not reducible to weighing and balancing options. But what role?

If we truly want to incorporate parents' emotions into life-or-death decisions for newborns and babies who cannot speak for themselves, we need to think very carefully about what emotions can and cannot do — what roles they play in informing us about our own needs, versus the needs of others. To meet our ethical obligations to the child as well as to the parents, we need to avoid developing an idealized account of the role that parents' emotions ought to play in guiding such decisions, since there are important limitations to emotional intuition in such cases. To consider the moral guidance provided by emotions in such decisions, we need to clarify what the standards would be for a "good" decision in such difficult cases. Following Higginson and Browning and colleagues, I agree that while there are several important values at stake in such decisions, the two most important ones are the quality of life for the child and respecting the deep values of the parents. A good decision is one that serves these ethical goals. In these two cases, emotions, I will argue, helped very much in illuminating the parents' values, but they were not particularly informative about the suffering, or quality of life, of the child.

EMOTIONS AND THE VALUES OF THE PARENTS

Let us begin by presuming that detached reason is morally insufficient, that our emotional views, as argued in feminist philosophy, are essential for perceiving moral salience.⁵ They help us notice and then focus on the attachments and vulnerabilities that are most important to us. When people become emotionally detached, they also become impaired in perceiving the suffering of others.⁶

Still, while emotions might help us notice what is morally or humanly relevant, they are not always reliable indicators of our deep and long-standing values. Consider how romantic passion or fear of loss compel our actions and even give us a sense of certainty — and yet both can also feel quite alienating in retrospect. The strength of an emotional feeling does not necessarily reveal how integral the emotional view is to our internal beliefs and values. Consider Ronald Dworkin's famous example of a devout Jehovah's Witness whose fear of dying leads him to seek a blood transfusion.⁷

Annie Janvier's husband felt such a strong emotional intuition that he felt certain of the decision to prolong the baby's life. At that moment in time, there was no way for him or anyone else to know for sure if this intense conviction was or was not truly reflective of his authentic, or most core, values. In fact, there are reasons to be concerned that his emotions resembled romantic passion or fear of loss that blinds us, rather than curiosity or *agape* — emotions that more consistently reveal our values to us. After all, it was seeing the baby suck the pacifier — which could have been a reflex — that moved him so deeply, shutting out all other thoughts. According to his wife, "he could not let go even if she was bloated, marbled, and pale! I was angry that a knowledgeable physician could interpret these details in such an irrational manner. . . ."

Fortunately, we need not resolve the question of whether the husband's strong feelings in isolation were a reliable basis for this crucial decision, because he didn't make the decision in isolation. Rather, Annie Janvier and he made the decision together. Perhaps *her* integration of thought and feeling gives us a more useful model for how emotions can reveal core values. Janvier, despite her self-described traumatized numbness, was not completely emotionally detached. In particular, she was moved *emotionally* to change her mind based on her husband's response. She engages with his feelings in a way that exemplifies thought processes through which emotions become internal or authentic reasons to make a decision: "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." Janvier's decision making here is guided by core values. While she remains aware of how dismal the prognosis is, she decides that her love of her husband calls for her to be on the same page with him. This illustrates reflective, emotion-guided reasoning.

This example points out that by looking at emotions as social transactions among loved ones, rather than merely private experiences influencing an individual's decision, we are more likely to identify reasoning about emotions, rather than just emotions themselves, as the driver of decisions. One person's feelings can then be a good reason for another to make a decision, even if the first person wasn't able, at the time, to be reflective about them. This is especially relevant for parents making such frightening decisions — when parents are fortunate to have more than one person to help make the decision, this interpersonal process can help transform gut feelings into a reasoned decision by the couple, or in some cases even a larger family group.

EMOTIONAL INTUITION AND THE CHILD'S QUALITY OF LIFE

According to Browning and colleagues, research reports that, in making such difficult decisions, parents care most about trying "to ascertain and predict their child's expected quality of life." Higginson interprets these two cases as showing how parents' emotions helped them to empathize with their children, and thus put them in a better position to make decisions based on what matters most. I am afraid that I must respectfully disagree, since I think that these decisions, inspired by strong parental emotions, were not tracking information about the child's quality of life. In fact, while I have just argued that these two cases illustrate parental love, and I have no doubt that these parents do empathize with their children, these cases, as described, are not illustrative of empathy for the child's suffering or future quality of life.

Higginson argues that parents, precisely because they "feel connected to their child" are "usually in the best position to balance the suffering of their child with the hope for the child's future after recovery." This is a very strong unproven claim that needs to be carefully parsed theoretically and examined empirically. Instead, Higginson goes on to say that parents can do this because of their empathy for the child. What kind of information, what model of understanding should this empathy involve? He ends the article without going to this crucial next step, leaving this reader with the impression that he feels that the parental emotion and concern described in the two cases are demonstrations of such empathy.

While I think that the parental feeling described in the two cases were demonstrations of love, and of deep parental values — these parents realized how important saving the child was to them — I do not see this

as an example of empathy. In fact, if we take the term empathy to mean, specifically, understanding what in particular another person is experiencing and feeling, there was almost no information in either of these two cases about what the babies were experiencing, and even less about what they might feel in the future. These decisions necessarily needed to be made in the face of tremendous uncertainty about what these two children's lives would be like. Given radically insufficient information, various emotional processes fill in, but these processes are not empathy. For example, Higginson rightly worries that physicians in such cases *project* their own "personal intuition," biased by their own valuing of intelligence and ability. He even offers a crucial correction to such unreflective use of intuition — seek more information. He emphasizes data that report that extremely low birth weight infants with disabilities show the same quality of life as age-matched controls. I would argue that it is in seeking this kind of information, rather than in acting out of any gut feeling *per se*, that parents too are more likely to empathically grasp the needs of the child.

Elsewhere I have argued that empathy is a mode of understanding that integrates emotional resonance and curiosity to learn more about what in particular another's life is like.⁸ Sometimes, in a rush to idealize emotions over against detachment, we forget that empathic understanding requires different things in different situations. In this situation, what was needed was less emotional intuition and more gathering of *empirical* information about other people's lives.

Thus, we wind up with an important conflict. In these cases, the parents' urgent emotional responses were important moral compasses expressing the values at stake, but this same emotional urgency put them in a worse position to reflect on the data about the child's quality of life. This is precisely what Cohn courageously shows. She vividly describes being unable to seek and take in the very kinds of information that might help with this difficult balancing. Cohn writes, "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*."⁹

Interestingly, Cohn goes on to question whether parents, *precisely because of how much they care*, may in some instances be temporarily *incapable* of taking in such information. Inadvertently, she raises a topic with enormous ethical implications, since a lack of capacity would undermine parental rights to make the decision for the child. We need to take care not to reify as incapacity the parents' difficulties in absorbing information, lest we fail to examine how we as caregivers might help parents at precisely such moments. Parents might need extended support networks to comprise a capable unit for decision making, just as Janvier and her husband did better together than they each seemed capable of doing on their own. Parents might need their own emotional suffering to be addressed more thoroughly than caregivers often do. And people in distress may need other ways of absorbing information — patient-centered decision aids have been shown to help in such cases.¹⁰ We need to address these needs of parents before coming to any conclusions about their decision-making capacities.

CONCLUSION

These articles beautifully demonstrate how parents' emotions humanize the most difficult ethical decisions imaginable. They also suggest ways that emotions are indicators of, and prompts for discussion of, the parents' values. This serves one crucial goal of decision making. However, we should be careful to avoid conflating this with emotions serving another crucial goal — trying, however approximately, to grasp the child's quality of life. Granted, appreciating the child's value is perhaps the necessary grounds for *motivating* an empathic gathering of information. However, the former is far from sufficient for the latter, since the former is about what the *parent* cares about, and the latter is about what the *child's* life will be like.¹¹

Finally, importantly, even my attempt at precision on this matter needs to be contextualized against the very profound shift in perspective that, as Browning and colleagues suggest, such tragic choices require. They point out how little we know of how parents actually get through this kind of experience. They usefully note, "parents described the process less in terms of having 'made a decision,' and more in terms of a struggle to find their bearings. . . . in an uncertain moral universe." These articles by courageous caregiver-

parents sharing their most difficult moments should serve as a wake-up call to other caregivers to make sure that we support parents and welcome their emotions at such times.

NOTES

1. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE*.
2. F. Cohn, "Real Life Informs Consent," in this issue of *JCE*.
3. J.D. Higginson, "Emotion, Suffering, and Hope: Commentary on 'How Much Emotion Is Enough?'" in this issue of *JCE*.
4. D.M. Browning et al., "Reflections on Love, Fear, and Specializing in the Impossible," in this issue of *JCE*.
5. M.O. Little, "Seeing and Caring: The Role of Affect in Feminist Moral Epistemology," *Hypatia* 10, no. 3 (1995): 117-31.
6. J. Halpern and H. Weinstein, "Rehumanizing the Other: Empathy and Reconciliation," *Human Rights Quarterly* 26, no. 3 (August 2004): 561-83; J. Halpern, *From Detached Concern to Empathy: Humanizing Medical Practice* (New York: Oxford University Press, 2001); M. Nussbaum, *Upheavals of Thought* (Cambridge, U.K.: Cambridge University Press, 2001).
7. R. Dworkin, *Life's Dominion* (New York: Alfred A. Knopf, 1993), 226-7.
8. Halpern, *From Detached Concern to Empathy*, see note 6 above.
9. Emphasis added.
10. A. O'Connor et al., "Decision aids for patients facing health treatment or screening decisions: systematic review," *British Medical Journal* 319 (1999): 731-4.
11. This distinction is easier to see when we don't sympathize with a parent's judgment — as for example, when a parent sees a child with mildly short stature as likely to be irreparably socially rejected and subjects the child to very aggressive treatments, while data actually report that shorter children do very well socially if they are otherwise psychologically supported. See E. Parens, "Authenticity and Ambivalence: Toward Understanding the Enhancement Debate," *Hastings Center Report* 35, no. 3 (2005): 34-41; D.G. Gill, " 'Anything You Can Do, I Can Do Bigger?': The Ethics and Equity of Growth Hormone for Small Normal Children," *Archives of Disease in Childhood* 91, no. 3 (2006): 270-2; L.D. Voss and D.E. Sandberg, "The Psychological Burden of Short Stature: Evidence Against," *European Journal of Endocrinology* 151 (2004): S29-33.