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Emotion, Suffering, and Hope: Commentary on "How Much Emotion Is Enough?"

Jason D. Higginson

Jason D. Higginson, MD, is a Lieutenant Commander in the United States Navy at the National Naval Medical Center and an Assistant Professor of Pediatrics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland, and a Sullivan Scholar in Bioethics and Health Policy at the Neiswanger Institute for Bioethics & Health Policy, Loyola University Chicago Stritch School of Medicine, jhigginson@usuhs.mil. ©2007 by *The Journal of Clinical Ethics*. All rights reserved.

Informed consent in the neonatal intensive care unit (NICU) often involves a frenzied discussion just prior to a pre-term delivery or following a severe worsening of an infant's illness. This can be a difficult process. In the narrative, "How Much Emotion is Enough?" Annie Janvier aptly points out that these discussions may not be an ideal example of informed consent.¹ This often-rushed process is complicated by the emotion that is inevitably involved. Parents may appear to lack insight into the outcomes that neonatologists believe are inevitable. This may lead the parents to make decisions that seem inappropriate to the medical team. The main question posed by the narrative is, *Can a rational decision really be made at such a time?* Janvier relates her own experience, as a neonatologist and expectant mother of a very pre-term neonate. Beautifully described in the essay are the numerous and conflicting emotions families can go through when making these decisions. The author ultimately concludes that emotion and medical knowledge are equally important decision-making tools.

The birth of a child is the birth of the hopes and dreams that parents have for themselves and for their child. These dreams can be shattered when something goes wrong. Discussions of informed consent in neonatology often focus narrowly on outcome data. This can lead discussion away from an analysis of what constitutes an informed and valid decision. These discussions lack an examination into the presuppositions that physicians bring to the counseling process. "How Much Emotion Is Enough?" illustrates some of these assumptions.

There is an underlying belief that knowledge of medical facts makes physicians experts at their application. Janvier notes that her husband "is the master of evidence-based medicine" and asks, "What about *our* informed consent?" These comments suggest that their knowledge of neonatal outcome data in some way makes this a less-valid process. Medicine often has an impoverished and unexamined view of human existence. Medical research narrowly focuses on issues that can be measured. As Janvier points out, most deci-

sions in life are not based on measurable quantities. However, this does not make these decisions irrational, as the author contends. A person's desires and preferences are not necessarily irrational because they are not based in scientific fact or because they have an emotional element.

An ethics mentor of mine once pointed out that you cannot prove that one flavor of ice cream is empirically better than another. Yet in the NICU, outcomes data are often interpreted in terms of "good" and "bad," demonstrating a non-empiric or emotional component in research. Notably, NICU research typically joins death and disabilities as a single, value-laden categorical variable: "bad outcomes" or "poor outcomes." I noted this in my training first as a pediatric resident and subsequently during my fellowship in neonatology. The view often presented to those in training is that disability is the worst fate that can befall a pre-term infant.

This view of disability is further advanced in the way pediatric society guidelines are discussed and applied. That is, in cases when a "poor prognosis" is expected, there is no obligation to intervene. What is a *poor prognosis* and what does this mean in practice? Many physicians would likely respond that disability makes for a poor prognosis. Based on this, the rational decision is not to initiate care or remove support if disability were the expected outcome. This has been reported in a survey conducted by Morse and colleagues.² The survey asked pediatricians and obstetricians to estimate neonatal handicap rates after delivery at different gestational ages. Physicians consistently rated the level of disability as much higher than the actual rates found in the medical literature. Why is this the case?

Combining death and disability as "poor" outcomes leads providers to overestimate the disabled proportion of NICU survivors. There are a large number of "poor" outcomes at the limits of viability, but separating death from disability is not easy with casual reading of the available research. The twenty-second to the twenty-third week of gestation is considered the lower limit of viability for a neonate. Survival increases with increasing gestational age, but disability free survival does not seem to be affected until the twenty-seventh week. That is, if survival does occur, disability rates are the same across these low gestations up to about 27 weeks gestation.³ This is not widely appreciated.

The reason resuscitation is considered "optional" at the lowest gestational ages has more to do with survival than with disability. At lower gestational ages, when death is very likely, we assume that the intervention necessary for the preservation of life is often painful and likely to lead to significant suffering. This is an assumption, but likely a true one. The reason intervention goes from optional to obligatory at 25 weeks is not because disability rates drastically change. Rather, it is because survival improves dramatically. The suffering an infant will likely sustain in efforts to allow survival can be seen as too great to justify intervention if the probability of survival is low.

Certainly the effects of future disability play into decisions made in the NICU, but to what extent should they? Is this an overemphasized point in counseling parents? Does disability lead to suffering? That is the assumption made by many in neonatology, usually based on little more than personal intuition. Physicians are a group that generally place high value on intelligence and ability, and this may color the way we view outcomes. There is emerging evidence from a group led by Saigal that disability may not be as disruptive to future quality of life as physicians generally think.⁴ These studies consistently report that many extremely low birth weight survivors from the NICU rate their quality of life similarly to age-matched term controls, despite empirically higher levels of disability. The authors report this trend in numerous studies, from early childhood into now early adulthood. Why, then, do we consistently claim disability is a "bad" outcome? Certainly it is not the desired outcome when we treat a patient. However, Saigal's evidence suggests that life with disability may not be as filled with suffering as most physicians assume.

Why is parental informed consent so important in the NICU? Why do we not attempt to intervene with all infants, despite parental desires? Why do we not withdraw care when we feel it is the most rational decision, even if parents disagree? The answer is that parents are the most likely to feel connected to their child, and thus are usually in the best position to balance the suffering of their child with the hope for the child's future after recovery. Janvier notes that she remembers the pressure to demonstrate that she was a good parent while simply wanting the final verdict. The NICU can be an overwhelming, anxiety and guilt

inducing environment for a parent. Acknowledging this with parents and assuring them that no one expects them to demonstrate their worthiness as parents may help them through the NICU course and during other unstable times. Parents are needed to help direct the course of care for their infant. They usually are the best advocates for their child.

I agree that emotion is an important part of decision making in these complex situations, as Janvier suggests. However, I do not believe that it compromises rationality. It allows for an appreciation of both suffering and hope.

I think at times in the NICU we overcomplicate the informed-consent process by relying on statistics and disability rates while ignoring our own inherent biases. Outcome statistics are an important part of the process, but certainly not the only part. Often forgotten in these discussions of statistics are the child and the suffering that may be ongoing.

A valid decision begins with empathy for the child. Few decisions in the NICU are clear-cut. As pointed out in "How Much Emotion Is Enough?", knowing the final outcome does not validate a decision. The decision becomes valid when it is made thoughtfully and with the child in mind.

DISCLAIMER

The opinions expressed herein are those of the author, and are not necessarily representative of those of the Uniformed Services University of the Health Sciences, the Department of Defense, or the United States Navy.

NOTES

1. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE*.
2. S.B. Morse et al., "Estimation of Neonatal Outcome and Perinatal Therapy Use," *Pediatrics* 105, no. 5 (May 2000): 1046-50.
3. M. Hack et al., "Neurodevelopment and Predictors of Outcomes in Children with Birth Weights of Less than 1000g," *Archives of Pediatrics and Adolescent Medicine* 154 (July 2000): 725-31; H. MacDonald et al., "Perinatal Care at the Threshold of Viability," *Pediatrics* 110, no. 5 (November 2002): 1024-7.
4. S. Saigal et al., "Transition of Extremely Low Birth Weight Infants from Adolescence to Young Adulthood," *Journal of the American Medical Association* 295, no. 6 (February 2006): 667-75; S. Saigal et al., "Self-Esteem of Adolescents Who Were Born Prematurely," *Pediatrics* 109, no. 3 (March 2002): 429-33; S. Saigal et al., "Impact of Extreme Prematurity on Families of Adolescent Children," *Journal of Pediatrics* 137, no. 5 (Nov 2000): 701-6; S. Saigal et al., "Differences in Preferences for Neonatal Outcomes Among Healthcare Professionals, Parents and Adolescents," *Journal of the American Medical Association* 281, no. 21 (June 1999): 1991-7.