

Deserve's Got Nothin' to Do With It: A Philosopher Visits the NICU

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Abstract

After the death of my daughter Zoe in neonatal intensive care unit (NICU), a colleague asked me whether my status as an academic philosopher changed my experience in the NICU. In this short narrative, I outline 5 ways in which philosophical perspective helped me understand and cope with our hospital experience.

Keywords

patient perspective/narratives, pediatrics, end-of-life care, challenges

In March 2014, my daughter, Zoé, died after 5 months in the neonatal intensive care unit (NICU). Zoé was born in November at 26 weeks gestation and less than 500 grams. During her short life, Zoé almost died several times, and in March, her lungs worsened to the point where there was no reasonable hope left.

A few months after her death, I attended an academic conference, and in the course of expressing sympathy for what had happened, one of my friends asked me how being a philosopher helped me deal with the everyday realities of the NICU. My initial answer was, “Not very much.”

That is still my answer. Despite the fact that I have not led a charmed life, nothing prepared me for the NICU. If I had to sum up my own experience, I would say that the NICU is a place where there are a lot of facts to face, and if you are unlucky, most of these facts (e.g. your child's everyday suffering, her imminent death, her possible life, your own future prospects as a parent) are difficult ones, particularly when framed against the background of one's own hopes and dreams about having a child.

Still, it occurred to me that my friend's question was an interesting one: Upon reflection, my academic training had indeed been useful at several points in my clinical experience. In fact, there were 5 key ideas that I had learned during my studies that were especially helpful for dealing with life in the NICU.

1. *More information is often not better.* Sociologist of knowledge Bruno Latour has an illuminating remark about this:

As long as I'm far from the hospital, I never know what I've got. My words have no truth-value . . . they don't take on any weight

until I enter the institution, until I plug in my arm, my heart, my teeth, my liver, into this or that instrument. I can believe in my own health at home in my own bed, but I only know with certainty at the price of a meeting with the Proof-Makers in their City, to employ Bachelard's felicitous phrase (1) (p. 85).

As anyone who has visited an NICU knows, a great deal of “proof making” in this sense is always already going on at all times with any child who is there. Zoé produced a constant visible feed of data on the monitors, which mediated all of my interactions with her. In retrospect, however, the information that was the most demoralizing came from reading meta-analyses about premature babies—the more time I spent in the NICU, the more I found it to be dispiriting and unhelpful to read about the (grim) prospects of babies like Zoé. In the general sense, parents have to face the facts in the NICU, but it is neither helpful nor productive to search for all possible facts that can be found.

2. *Scientists (and, by extension, physicians) are puzzlers, but not all puzzles are amenable to being solved.* In *The Structure of Scientific Revolutions*, Thomas Kuhn notes that what scientists do, fundamentally, is solve problems within the structure of a particular discipline (2). A corollary of this is that

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there are certain kinds of problems that are legitimate within the structure of the discipline (“When should we give steroids to premature babies, and how much should we give them?”), but there are other problems that are less legitimate. These include topics which the discipline itself has difficulty addressing (“How much are the babies suffering?”) and topics which are simply beyond the bounds of what the discipline can be expected to accomplish (“Is our baby ever going to be OK?”).

One thing that helped me in the hospital enormously is that unlike some parents, I usually did *not* expect physicians to be able to act outside the scope of their frameworks. In general, science is most powerful when it is dealing with the “known unknown”: problems it knows how to solve or problems for which it has some useful initial hints about how to proceed. Beyond this, in the terrain of the “unknown unknown,” it tends to get bogged down.

3. *As facts make their way from the laboratory to the academic journal to the patient, they tend to become more certain.* In *Laboratory Life*, Latour and Woolgar trace the evolution of a scientific statement from something that might possibly be true (they call this a type 1 statement) to something that has so much “truthiness” that one would be scolded for even doubting it (a type 5 statement). As the statement grows more certain, the initial doubts and nuances disappear, and the statement becomes conventional wisdom (3).

I observed this phenomenon in the NICU, and perhaps the most striking illustration of this for me was the practice called “kangarooing,” in which parents are encouraged to hold their premature babies “skin to skin” against their bodies. The appeal of kangarooing is obvious; when your child spends much of her time inside an incubator or wired up with various monitors, it would, in theory, be nice to have direct, “natural” contact with her. In our case, the nurses assured us that we *should* kangaroo, as studies had clearly demonstrated it to be beneficial to the babies.

For us, the problem with kangarooing was that it was a miserable experience. Zoé was very sick: any romantic illusions you might have about holding your baby skin-to-skin are dispelled quickly once desaturation alarms start wailing and monitors begin to flash. It’s not an unmediated experience, either, because the whole time, your baby is still connected to her monitors, respirators, and drug-delivery systems, and you’ve got to be careful not to disconnect any of this stuff. We endured this since we thought it might be beneficial for Zoé.

After we had one kangaroo to many, I decided to check the journal articles on this practice. As it happened, the evidence indicated that kangarooing had delivered some marginal benefits among relatively healthy preterm infants (4). This was not what we had been told: Clearly, as the

practice made the leap from the hospitals which pioneered it to the medical journals to our hospital, it also transitioned from a possibly helpful innovation into a parental obligation.

4. *In any large institution, there’s only so much room for individual difference.* In *Discipline and Punish*, Michel Foucault writes about the emergence of the timetable: “Its three great methods—establish rhythms, impose particular occupations, regulate the cycles of repetition—were soon to be found in schools, workshops, and hospitals . . . [these institutions] extended the life and the regularity of the monastic communities to which they were often attached” (5) (p. 149).

In the NICU, the hospital has its rhythm, and if you don’t fit into it, there’s not much that can be done. For example, Zoé would get hungry every 2.5 hours. Her milk, however, would be delivered in 3-hour intervals by the nurses. Zoé would get upset about this, which was no laughing matter, as when you can’t breathe properly to begin with, getting upset has a serious negative impact. The doctors and nurses who looked after Zoé were sympathetic about this problem, which we were impassioned about, and they did their best to make sure that she received her milk at a nonstandard interval. But when you are a part of a big machine like an NICU, even what Foucault might call the “sovereign power” of the sympathetic doctor can’t do much against the power that the institution’s own ritual exerts. The milk always comes on schedule, regardless of what anyone may want.

5. *It’s not a just world.* In his critical analysis of the benevolence of God’s creation, David Hume comments:

Pleasure, scarcely in one instance, is ever able to reach ecstasy and rapture; and in no one instance can it continue for any time at its highest pitch and altitude . . . But pain often, good God, how often! rises to torture and agony; and the longer it continues, it becomes still more genuine agony and torture. Patience is exhausted, courage languishes, melancholy seizes us, and nothing terminates our misery but the removal of its cause . . . (6) (p. 65)

This statement, and Hume’s analysis more generally, captures an important truth: despite how we might wish to shelter ourselves from it, there’s a great deal of suffering in the world, and sooner or later we have to reckon with it somehow. Zoé suffered a lot, and my wife and I suffered as well, although much less than Zoé did. It’s difficult to square so much suffering with a positive worldview, but if you’ve already been steeped in a certain amount of pessimism and doubt from the outset, it gives you some resistance. I’m sure that some NICU families are comforted by their faith; I was more comforted by my lack of faith than anything else. One is reminded the scene in *The Unforgiven* in which a man,

about to be shot, says to Clint Eastwood, "I don't deserve this!" Eastwood's response is a memorable one: "Deserve's got nothin' to do with it."

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