

Stop Experimenting on My Baby!

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Abstract

Having a small sick baby in a neonatal intensive care unit can be an extremely difficult experience for any family. A minority family brings to this setting the additional burden of a concern that racism may affect the care their child receives. While the technology may be overwhelming, the unique rules and an apparent disparity in the enforcement of these rules can suggest discrimination. In some cases, these parental perceptions lead to a charge of experimentation. An increased understanding by health care providers of the cultural differences and life experiences that families bring to stressful situations can improve communication. **Key Words:** Bioethics, neonatology, minorities.

I WOULD LIKE TO RELATE SOME OF THE ISSUES that I, as a neonatologist, encounter when dealing with some of the families who have small, sick neonates in the intensive care unit. I want to preface this discussion by acknowledging that having a critically ill child can bring out both the best and the worst in people. I say this knowing that it often takes marked restraint not to become angry when a parent launches into a thinly veiled personal attack.

Let me start by sketching the setting. The neonatal intensive care unit (NICU) is large, busy and, unfortunately, rather noisy. Thirty to forty babies are in various states of health. Most live in incubators, attached to monitors for heart rate, breathing, oxygenation, and temperature. They have intravenous catheters in veins and plastic tubes in blood vessels in the umbilicus. Gastric tubes are coming out of their noses, and a number of the babies are attached to respirators. Alarms go off every few minutes. Imagine yourself as a 17-year-old African American mother who delivered a two-pound baby girl—your first pregnancy. You are in your last year of high school and your boyfriend, the father of the baby, hasn't been all that interested in you since you got pregnant. Although you did go to some of your prenatal vis-

its, others were at times that interfered with school or being with your friends. Labor and delivery were scary and painful, and you delivered your daughter in an operating room filled with doctors, nurses and machines. You barely saw your baby at her birth, and a group of people with masks and caps took her away after hovering over her for what seemed an eternity, right after her birth.

With this introduction to neonatal intensive care, this mother must try to understand who we are and what we do. But why is this an issue unique to minorities? Surely, white Upper East Side investment bankers don't come with a prior knowledge of neonatal intensive care. What they do come with is an implicit trust in medical technology and in our ability to heal. For those families, any failure implies we didn't do everything we could. We weren't smart enough, skilled enough, computerized enough, technical enough. For our young African American mother, at issue is not our abilities but our motivation. That's not to say that we won't be questioned about our skills or that our young mother won't realize that various doctors and nurses have varying capabilities. It's just that there is a more significant problem that we must always keep in our minds. Our young mother does not believe that my primary goal is to care for her little daughter with all my heart and soul.

What do we do to make her mistrust us? Is it the overwhelming technology that comes between us? We assume it's comforting to see our high-tech response to a two-pound baby, but in fact,

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our mastery of this technology makes our young mother feel frighteningly powerless. Every parent of a sick baby feels powerless. We know this and we help parents verbalize this feeling. However, this is more difficult with our young mother, who is not willing to discuss her feelings with me. I don't blame her. She certainly doesn't know me, and there is obviously a long history of inequality and racism that clearly places our ability to communicate openly in question. For most families, their lack of power doesn't immediately translate into an adversarial relationship with the health care provider. It is more often an emotional response to the "bad luck" of their being in such a situation. The young African American mother, however, sees me as part of a technology not to be trusted. I am not only powerful but "different." As in any situation of unequal power, it is not unusual to examine motives.

Not only do we overwhelm her with our technology, but the NICU is a place with rules that are different from those at home. We demand strict adherence to the limits we place on visiting hours, the number of visitors, the noise level, etc. And then we appear to enforce these rules unequally. We are much less likely to ask the extended family of the Upper East Side investment banker to leave than the lively young cousins of our 17-year-old mother. Our young mother sees that I might spend 10–15 minutes speaking with the family of the investment banker and only a couple of minutes with her. It doesn't matter that they engaged me in a long discussion of medical details and that she had little to say. From her perspective, I've chosen sides.

All of this leads to the title of this talk, "Stop Experimenting on My Baby." Over the last decade, I have been accused (as have many of my colleagues) on more than one occasion, of experimenting on an infant. The scenario is often similar— a baby has been very ill and in our unit for an extended period of time, and a small group of African American mothers, all with babies in the NICU, have become close friends. Each has had something happen to her baby which we, the health care team, have been unable to clearly explain or prevent. Maybe her baby had an intraventricular hemorrhage and developed hydrocephalus, or a patent ductus arteriosus failed to close spontaneously and heart surgery was required. A central intravenous catheter may have become infected with yeast and we are having difficulty finding sites for IVs, so we shaved a part of the baby's hair. Maybe we are keeping a baby alive on a respirator in a situation where discontinuing support is generally felt to be unethi-

cal. Needless to say, never have we "experimented" in the medical/technological sense.

In some of these cases, the accusations are not made directly but are overheard in the parent lounge by a passing staff member. In other cases, there is a direct and angry confrontation over this issue: How can I not see or believe that we are experimenting? I, as the master of this technology, can't answer this or other seemingly easy questions. Yet I have answers for everyone else. Other babies are getting better. Only the babies of African American mothers seem to have these kinds of problems. Any failure in this unfathomable and foreign NICU must be because I can't be trusted. It happened because I allowed it to happen. Are they right and am I wrong? The quick answer would be no, but that might not be totally true. There is an element of truth in the accusation and it certainly has solid historical roots. Remember the delivery of this tiny baby. We presented ourselves as "automatons" sweeping this baby off to the NICU, promising to apply our high-tech miracle cures. We tried to be compassionate, but that is so hard in the setting I've described. Sure, we hedged and gave numbers of survivors and all the rest, but we-the-system held out hope. However, a high-tech system is not infallible, so, not surprisingly, the time comes when we "cannot be trusted." As scientists and technocrats, when "things" don't go right, we must be doing something other than curing. To our young mother, experimentation is the obvious answer. To me, each patient is an "experiment" (but not in the layperson sense), whom I hope to cure with tools that don't always work. My motives are simple and sincere, but they become entwined with hundreds of years of painful history and experience. To my young mother, the same scenario, without trust, is also an experiment. But this experiment isn't working, and I shouldn't have done it to her baby.

Do I have a solution? Not exactly! I don't think we will be able to really gain the trust of our minority patients until it becomes clear to them that the medical system is designed fairly for all people. There is no use simply claiming that it is. In the interim, I believe that health care providers can diminish the likelihood of being accused of experimentation by recognizing the bases of that charge. It should not seem incomprehensible to each of us that patients don't trust our motives. Recognizing that fact will probably improve our ability to communicate and increase our sensitivity to important cultural differences and the generalized effects of discrimination.