Managing Endings in the Beginning: Ethical Reflections on Neonatal Intensive Care

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MANAGING ENDINGS IN THE BEGINNING: ETHICAL REFLECTIONS ON NEONATAL INTENSIVE CARE

INTRODUCTION

In the neonatal intensive care unit (NICU), the lights are dimmer (each patient recuperating from a vast array of co-morbidities, perhaps even from surgery), the voices lower (lest the staff startle the newly born who necessitate copious amounts of sleep), and the atmosphere tenser. As rounds progressed and my eyes, like those of the prisoners in Plato's "Allegory of the Cave," became adjusted to the "shadows on the wall," the moral temperature would only grow hotter (damp, almost tangibly wet) on the unit whose primary concern was the treatment of society's weakest and most vulnerable.

The stakes are immeasurably high in the NICU. Ethical issues abound for these newborns, who spend their earliest days depending, for the very first time, on someone other than their mothers for continued biological existence. Determinations over the intensity of treatment, whether to include resuscitation measures in the delivery room, the transferring of care, and the prospective possibility of ever leaving the unit are all concerns that plague the NICU on the daily basis. Both parents and medical professionals struggle to determine just how much technology is available, medically appropriate, and morally reasonable. Countless concerns – practical and existential alike – infest this arena of care: How much suffering is acceptable for *this* newborn? According to what, exactly, is it measured? How can we, as medical professionals, enter into the chaos of someone who is incapable of communicating with us?

QUALITY OF LIFE: A DIFFICULT DISCERNMENT

Dialogue concerning the treatment of critically ill newborns has historically centered on the role of disability in determinations about what medical treatments are in the best interest of the neonate. Parents are typically accorded the responsibility of making such determinations for their children, based on their presumed concern for their well-being. Determining the kind of life worth living for someone whose values remain unascertained is no small task. Indeed, it is excruciating. Witnessing the placement of a PEG feeding tube and mechanical ventilation on a (barely) three-pound, one-day-old human being all-too-vividly exemplifies the benefits and burdens of contemporary biomedical technology and its seemingly limitless capabilities.

According to Dr. C. – a thoroughly melancholic fellow who no doubt gives both heart and soul to his patients, perhaps to the point of existential and spiritual exhaustion – there has arose some form of ethical issue in the NICU "every day for the thirty years I have been here." Be it low birth weight (a strong predictor of illness and death affecting some ten percent of all live births), congenital abnormalities (traced to the inheritance of defective genes, chromosomal abnormalities, and environmental factors – such as exposure to in utero viral infection or chemical exposure – affecting four percent of the 3.5 million infants born each year), or other medical anomalies, these "little ones," as Dr.

C. affectionately calls them, pose serious moral questions to the traditional standards of treatment imbedded in systemic protocols.

“WE *DON’T* LET BABIES DIE HERE”

The average stay in the NICU is, according to Dr. C., eight to eighteen days. At the conclusion of my first day of NICU rounds, I posed what I imagined to be a straightforward question: “How often do neonates perish in this unit?” Dr. C. grimaced, almost without hesitation (not an atypical facial expression for Dr. C., who seemed to frown more than smile, and to exhale with distress more than inhale or even blink). A disgusted look slowly, and painfully, overcame him. “They *don’t*. We *don’t* let babies die here. That would be ridiculous.” A few moments before, I shared with Dr. C. the statistic that one in five patients admitted to the (adult) medical intensive care unit perishes there. The logical conclusion, to my mind, was that some statistical value may also be true for the neonatal population. While I did not question Dr. C.’s remarks, his sentiments are most certainly untrue. (They must be.) It is surely a terrible and devastating event when the “little ones” are incapable of mustering up the biophysiological strength to survive beyond the first weeks of life. But it no doubt happens.

Dr. C.’s sentiments are hardly uncommon for staff in the NICU. The patients in this unit are exceptionally vulnerable. They will require constant monitoring, assisted ventilation, PEG feeding, perhaps multiple surgeries before they are “out of the woods.” This much is a given. But they are all, each of them, for the NICU clinician, *not* to die. While this mentality is encouraging (if only in a poetic sense), it is increasingly unhealthy, I fear. The forbiddance of death is, to be sure, no stranger to American culture. We take for granted that the elderly will eventually perish, that we will have to make end-of-life decisions for our parents, spouses, and similarly aged family members one day. But, as one NICU nurse put it, “palliative care was not designed for the neonate.” And to a large extent, she is right. There is something that feels terribly wrong about newborns, those individuals who have not yet had the chance to live, perishing at the beginning of life. What does it mean? Why did it happen? It seems morally outrageous. And yet it is no less avoidable.

BEGINNINGS AND ENDINGS

In the NICU as in any other medical unit, each intervention comes with potential benefits and possible risks, some foreseeable, others not. Decision making in such an uncertain context is often difficult, painful, and terrifying. The more power one has, the more powerless one feels. There is an irony. Perhaps more so than others, parents of critically ill newborns need regular consultation, counseling, and support. And they ought not to suffer alone. When the beginning marks the end, it is unquestionably the source of immense suffering. The tragic loss of an infant who was born only days ago transcends understanding, and will no doubt remain ambiguous for years to come. Anticipated grief is complex enough, and its unanticipated counterpart is hardly bearable.

For Dr. C. and others, death in the NICU marks failure – professional, personal, social, and moral. It disproves the “anything it takes” attitude that consumes modern medicine. When nothing can be done – or ought not to be done – it seems to leave an indelible mark on the soul of the practitioner. Yet, death is not, nor need it be, an enemy. For the neonate born with trisomy 13, for instance, a very short life consumed with immeasurable pain and suffering almost certainly proves a fate worse than death. As a non-medical professional, I can only attempt to ascertain and apprehend Dr. C.’s fear. I can even attempt to experience the existential nausea that is the product of newborn death. But reason, too, has spoken: sometimes death is the least bad outcome between two exceedingly poor options.

MORAL OF THE STORY

Many lessons can be gleaned from time spent in the NICU. One concerns the prudence inherent in knowing one’s limits. Both physically and emotionally, human beings can only take so much suffering, whether experienced or merely witnessed. Compassion fatigue is real, and its tentacles are far-reaching. A second lesson is that newborns who are not allowed a peaceful ending are not *ipso facto* better off than newborns who are. Life itself can be a burden too great to be borne. A final lesson concerns what these fragile individuals, most of whom will graduate from the NICU and emerge into the world, not without defect, but with courage and inner-strength that can only be imagined, can teach us: that what matters in life is what we do with what we have, however limited, however debilitated, however undesirable.

It is critical for bioethicists to remind NICU clinicians of the importance of inviting parents to share their experiences of making difficult decisions, of describing the medically reasonable treatment options clearly, succinctly, and compassionately, and of being a beacon of light in a unit all-too-often shrouded in darkness.