

Does It Matter if This Baby Is 22 or 23 Weeks?

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A 530-g girl born at 22 weeks and 6 days' gestation (determined by an ultrasound at 11 weeks) was admitted to the NICU. Her mother had received prenatal steroids. At 12 hours of age, she was stable on low ventilator settings. Her blood pressure was fine. Her urine output was good. After counseling, her parents voiced understanding of the risks and wanted all available life-supporting measures. Many nurses were distressed that doctors were trying to save a "22-weeker." In the past, 4 infants born at 22 weeks' gestation had been admitted to that NICU, and all had died. The attending physician on call had to deal with many sick infants and the nurses' moral distress.

Recent studies reveal that, with active treatment, infants born at 22 weeks' gestation can achieve survival rates of 25% to 50%.¹ Nevertheless, many hospitals do not offer life-sustaining interventions for such infants. For NICU clinicians, then, hospital policies and/or customary practices may conflict with clinical judgment and evidence-based outcome studies. Such conflicts can create moral distress. In this Ethics Rounds, we present a case that reveals these dilemmas and analyze possible solutions.

THE CASE

Domenica was 36 hours old when Dr Jane took over her care. Dr Jane was on nights, covering the delivery room and 72-bed NICU with only a junior resident to help her. Domenica was born at 22 weeks and 6 days' gestation (determined by an ultrasound at 11 weeks.) Her birth weight was 530 g. She was in her "honeymoon": stable on low ventilator settings at 30% oxygen. Her blood pressure was fine. Her urine output was good. The mother had received prenatal steroids.

When Dr Jane was charged with Domenica's care, she could feel the tension in the voice of the attending day team. The nurses were distressed that doctors were trying to save a "22-weeker." They thought that she could not survive and that treatment would just cause pain and prolong the inevitable dying process. In that unit, many infants born at 23 weeks' gestation received interventions and often survived, but the 4 infants born at 22 weeks' gestation that had been admitted to the NICU had died. Dr Jane spoke to Domenica's parents. They were realistic and knew she would probably die but they still hoped to beat the odds.

Dr Jane admired the NICU nurses. She knew how devoted they were and how they had to do all the tough work: pricking, poking, prodding, and suctioning while supporting and comforting the parents.

As midnight approached, Dr Jane realized that a disproportionate amount of her call had been spent managing the nurses' distress and validating their concerns. Her

abstract

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interventions seemed to work. She gradually felt less hostility from the nurses. Then, at midnight, the nurses changed shifts and it seemed a revolution was starting in the nurses' staff room. She realized that she would need to start counseling the new nurses; this was taking time away from her caring for the other 71 infants in the NICU.

On the spur of the moment, she changed the identification tag on Domenica's incubator, threw away the 1 that said "22 weeks," and replaced it with 1 that said "23 weeks." When a nurse asked, she said that the gestational age had been uncertain, and that Domenica was in fact probably born at 23 weeks' gestation. The nurse taking care of Domenica let out a big sigh and said, "Well, there is some hope. We are working for something." Moral distress disappeared for the rest of the night. Dr Jane told the resident, "Don't do this at home, not the best thing to do. I know I will pay for this, but I don't have any ideas for tonight, do you?"

Did Dr Jane do the right thing?

TRISHA PRENTICE, MD, PHD (NEONATOLOGIST), COMMENTS

The presence of moral distress is sometimes palpable when you enter a NICU; its influence can be far reaching and at times underappreciated. Traditionally, moral distress has been described as an organizational or systems problem that constrains a clinician into providing care that they judge is not in a patient's interests.^{2,3}

Professionals suffer when they believe that they are just causing pain with no hope of benefit. To respond to such distress, we must consider the appropriateness or accuracy of the judgment that there is no hope of benefit.

Much moral distress occurs within the context of medical uncertainty. A difference of 24 hours between the gestational ages of 22 weeks and

6 days and 23 weeks does not carry with it the significant change in prognosis worthy of the discrepant moral or emotional response that the altered bassinette tag brings.

Although Domenica may indeed be in a "honeymoon phase" and difficult days may be ahead, there is no evidence-based reasoning to justify the belief that a trial of therapy is any more unethical for her than for an infant born at 23 weeks' gestation. The arbitrary lines that institutions draw between impermissible and permissible (or between futility and hope) on the basis of estimates of gestational age may be well intentioned. They seek to limit expensive and burdensome treatments of limited benefit. Yet, we know that gestational age alone is inadequate for accurate prognostication.⁴ We do not yet know if Domenica will have a good outcome. We do know that not offering intensive care will surely lead to her death.

Despite these facts, the moral distress felt by the nurses is real. They remain certain in their conviction that intensive care is not in Domenica's interests because of their own fixed beliefs and values. The objective evidence is 1 thing. Their own experiences are another. They feel that they are being compelled to do the wrong thing and thus that their moral integrity is being compromised. This moral distress needs to be addressed and managed.

The physician has appropriately endeavored to hear and validate concerns and communicate clear goals of care. This has managed but not resolved the distress. The effects do not carry over from nursing shift to the next. Furthermore, the process is time consuming and likely emotionally draining for the physician.

This case highlights the hidden costs of moral distress. This case will have far-reaching ramifications. One could

imagine that the care provided to Domenica may differ from that provided to a more mature infant who is "worth fighting for." Should Domenica die, it would solidify the convictions of the nurses that treatment of "22-weekers" is futile. Her death would heighten the distress response should another infant with a similar gestation be admitted to the unit.^{5,6} The moral residue of Domenica's case may have a powerful effect on responses to future cases.

Meanwhile, the physician is struggling with the need to care for and support the morally distressed nurses while managing the needs of Domenica and many other patients in the unit. As the clinical leader whose tasks include managing the emotions of the NICU team, the physician is expected to deal with the moral distress. She is painfully aware that the nurses are hoping that Domenica's life-sustaining interventions will be withdrawn. The physician, however, believes that this infant might survive. The parents want Domenica to receive life-sustaining interventions. Thus, Dr Jane takes a moral shortcut and deceives the nurses about Domenica's gestational age.

By deceiving the nurses, the physician has killed her own moral integrity to protect the integrity of the distressed nurses, ensure ongoing intensive care, and allow her to do her job. This desperate strategy has also modeled deceptive conduct to an impressionable physician in training. The physician does not appear proud of her actions, but she struggles to find a more appropriate strategy to manage the interests of all involved. Given the situation, her actions were ethically appropriate. But they should be taken as a signal that there are deeper institutional problems in this NICU that need to be addressed.

Was there a better approach? It is unlikely that any single isolated intervention will be sufficient because

there are both organizational and individual factors at play. Institutions need to work hard to create ethical environments in which clinicians are trained to critically appraise ethical issues before they are raised by emergent clinical situations and where their concerns are heard and validated. Individuals need support to grapple with the subjectivity and uncertainty surrounding clinical decisions and be open to having their moral judgments challenged.

Although the experience of moral distress is real, it does not necessarily follow that the clinical plan or situation that causes that distress is itself unethical or requires change.⁷ When moral distress cannot be resolved because of moral subjectivity, individuals need to be mindful of the ways in which their own distress may affect others. These hidden costs of moral distress require further acknowledgment within the dialogue of moral distress.

JESSICA WALLACE, RN (NICU NURSE), AND PAUL MANN, MD (NEONATOLOGIST), COMMENTS

Deception in health care is rarely justified. The physician felt that, in this case, deception was justified, but it could have a big cost. If the nurses found out the attending physician had been dishonest about the gestational age, trust among the entire health care team and unit morale could be jeopardized.

As health care professionals, we have a duty to interact honestly with our patients, their families, and interprofessionally. This obligation was successfully met in the first part of the shift, with the physician candidly engaging the nursing staff, discussing the goals of care for the patient, and trying to address the nurses' clinical concerns. The importance of such deliberations to address moral distress and ethical dilemmas in the NICU cannot be overstated.⁸ Both nurses and

physicians report that lack of communication among team members is a common contributor to moral distress.^{9,10} Deception could end up exacerbating moral distress rather than relieving it.

The basis for the nurses' emotional distress in this scenario is likely multifactorial. Nurses frequently have a limited voice in decisions regarding resuscitative efforts and ongoing clinical care for extremely premature infants. They are expected, however, to unequally shoulder the burden of hands-on care for periviable infants and to meet the emotional needs of their parents even when they feel therapeutic interventions are not in the best interests of the patient.^{1,11,12} Routine neonatal nursing care (eg, obtaining cuff blood pressures and changing a diaper) can cause life-threatening skin breakdown in the friable, gelatinous skin of periviable infants. Standard nursing interventions such as intravenous insertions, laboratory draws, suctioning, securing endotracheal tubes, line placement, and the care of drains may cause significant pain and discomfort for infants. When infants are extremely fragile, even opening an isolette door can cause distress.¹³

There are not many evidence-based guidelines to support best nursing practice for periviable infants, leaving many nurses to feel that they are experimenting on patients by trial and error. Nurses who participate in such care often feel like they are abandoning their oath to "do no harm" and that painful interventions are not in the infant's best interest.

When the infants have a good chance of a good outcome, nurses feel that the pain is worth it.¹ A nurse in this case is quoted as saying, "Well, there is some hope. We are working for something." But was there actually more hope for an infant born at 23 weeks' gestation than for an infant born at 22 weeks and 6 days' gestation? Neonatal nurses frequently

overestimate poor outcomes for premature infants. Such outcome misconception is highest in nurses who infrequently care for periviable infants.¹⁴ Nurses frequently hear about patients who have poor long-term outcomes. They have limited opportunities to see NICU survivors who are thriving.¹⁵ It is always hard to know whether to base clinical judgments on peer-reviewed multicentre outcome studies that show improving outcomes for periviable infants¹⁶ or, instead, to base judgments on local experiences in their own NICU.

Educating the nursing staff on the unique clinical features of Domenica's case is therefore of the utmost importance. Some factors suggest a higher than average likelihood of a good outcome. Domenica is a girl of average birth weight who received prenatal steroids and was born at a center that provided active treatment at the time of delivery. These variables are all associated with an improved likelihood of survival.¹⁷ Furthermore, given the margin of error on ultrasound dates,¹⁸ Domenica could in fact truly have been born at 23 weeks' gestation.

Given all these factors, the doctor's deception in this case regarding Domenica's presumed gestational age, although expedient for a shift, becomes a missed opportunity for a teachable moment. Even if Domenica does well, the nursing staff will remain reluctant to provide treatment to other neonates born at 22 weeks' gestation. There is a clear disconnect between the physician's beliefs about possible clinical outcomes for neonates born at 22 weeks' gestation and the nurses who think that they "don't survive."¹⁹

There are almost no meaningful distinctions to be made regarding treatment of an infant born at 22 weeks and 6 days' gestation compared with an infant who has

achieved 23 weeks' gestation. The attending physician needs to continue to engage each shift of nurses with as much energy as she can spare; this is the only way to move the clinical care team away from gestational age-based thinking and toward a more holistic care approach that can accommodate the certainty of clinical uncertainty for all periviable infants.

KATE ROBSON (MOTHER OF PRETERM INFANT AND PARENT REPRESENTATIVE), COMMENTS

This case fills me with feelings of profound sympathy for all involved: the frightened parents, the exhausted doctor, the nurses struggling with their complex feelings, and, most of all, for the infant. A NICU can feel like a war zone at times with so many competing priorities and life-or-death situations. The drama that is the everyday normal of the NICU can cloud our sense of what is ethical in the moment.

If the noise around the central issue is eliminated; that is to say, if one takes away the fatigue of the medical staff, the lateness of the hour, the doubts or questions 1 caregiver had about intentions or abilities of another, the vulnerability of the parents, and the confusion around discussions of gestational age and viability, a clearer question is left: is it ever ethical for a doctor to lie to nurses about a patient? In this case, Dr Jane's lying is understandable but ultimately not justifiable. Honesty underpins the trust that is necessary for a team to work together in the NICU. Although it is sometimes difficult to figure out what the truth is, if we know something to be true, it must be acknowledged.

The intention of this lie was to protect the patient but the telling of the lie opened up numerous other channels of potential harm. Once the lie was uncovered, what would that do to the trust relationship between different members of the medical team? What

would it mean to the next family with an infant born at 22 weeks' gestation? Or the next family of an infant whom the doctor claims was born at 23 weeks' gestation? We cannot confine the impact of our actions to 1 moment or 1 relationship. The impact can continue to spiral in directions we could not possibly anticipate.

It is especially hard to deal with institutional ethical issues at the bedside. Ideally, ethical disputes and discussions should happen up the line (in general theoretical discussions) or well down the line (during debriefs of critical incidents). They should never happen in the room with the patient and family, where the focus should only be on the human being who needs care. The question of whether we should resuscitate "22-weekers" does not belong in the patient's room. If we create ample opportunities to discuss such questions in more appropriate environments, we will reduce the risk of them occurring in the moment when they are most likely to do harm. Creating these opportunities for exploring ethical issues far away from the bedside helps caregivers manage moral distress and be more present for their actual patient in the moment when their skills are needed.

I am the parent of an infant who spent time in a NICU. I am filled with appreciation for the actions of the doctor. Although I cannot find a way to ethically excuse Dr Jane, I see her as a doctor desperately trying to do the best for 1 small patient at a particularly significant and vulnerable moment. So, although it may seem like I am throwing this doctor under the bus, my emotional response is just the opposite. This is exactly the type of doctor I would wish for in this type of situation, one so dedicated that she or he is willing to entertain personal risk to help Domenica and her parents. My hope is that this 1 action did not lead to harm for this doctor, this infant, or this family and that it in fact advanced

or improved care for infants at the edge of viability by helping caregivers gain a new understanding of both the perils and possibilities facing infants born so early.

ANNIE JANVIER, MD, PHD (NEONATOLOGIST, CLINICAL ETHICIST), COMMENTS

We know gestational age is imprecise: approximately one-half of the "23-weekers" we take care of are in fact "22-weekers." We have also known for a long time that gestational age is only 1 of several factors that predicts survival.⁴ Despite our knowledge, many guidelines regarding intervention in the periviable period divide infants on the basis of completed 7-day periods of gestation. Such guidelines are neither rational nor ethically defensible.²⁰⁻²² Infants who are premature, like all other patients, should be assessed as individuals. The aim should be to establish individualized goals of care for each patient and with each family while recognizing uncertainty rather than acting on gestational age labels.²³

Dr Jane violated the nurses' trust. Honesty is essential for trusting, collegial relationships. But it is easy to say that as an outsider looking in. It is easy for me to write it while sitting in my pink writing chair with my perfect cappuccino. But what were Dr Jane's alternatives? None of them was much better.

Dr Jane was aware of the empirical evidence about gestational age. She listened to and discussed these issues with the nurses working in the evening. But taking more hours for "debriefing and educating" the night shift would have caused a threat to patient safety. The difficult shift described in the case was not the time or the place to question interventions for fragile infants at risk of death and disability.

These questions need to be discussed in other forums. I wonder if in a large

unit such as the one described, the “Time-out: not now/later” approach would have worked. This approach is easier in small open-bay units where all nurses can be reached at the same time and doctors know each nurse individually. In single-room large units, interactions are less efficient and personal. The organization of the provider shifts are also important: interactions between providers are often easier in units with 12-hour shifts and rotating schedules.

This “Time-out: not now/later” approach also requires that the moral distress be dealt with constructively. Taking care of ill patients is difficult. The nurse, resident, and physician taking care of Domenica need to know about goals of care. The other providers need to support them, not add fuel to the fire. Disorganized and excessive “group therapy” can be harmful. Too often, nurses will spend their well-deserved break speaking about “Domenica cases” instead of re-energizing themselves for the rest of their hard shifts. Doctors do the same. A frequent (and worse) situation is when doctors and nurses agree. This can result in unsolved frustration and resentment for those directly dealing with such difficult cases. But whose job is it (or should it be) to manage the nurses’ moral distress during evening and night shifts?

Perhaps Dr Jane felt the most distress that night? Many physicians would have just told the nurses to do their jobs, to face the music, and to stop complaining. Dr Jane took a more creative approach; one that was, admittedly, ethically questionable. By adding several hours to the gestational age, Dr Jane improved Domenica’s care but also created new problems that will have to be dealt with later.

OUTCOME OF THE CASE (ANNIE JANVIER)

I was biased in commenting on this case because I am Dr Jane.

After the end of the night shift, I disclosed to Domenica’s night nurse that I had changed the gestational age. I told her I was sorry, that I was exhausted, that I did not know what to do to help. I explained that Domenica was born at 22 weeks and 6 days’ gestation, ± 5 days, so she may well have been born at 23 weeks’ gestation. Domenica’s nurse smiled. She told me “her 22-weeker” was still stable and this made her hope for the best.

I have reflected a lot about this case. Had Domenica’s parents not been present at bedside, I would not have changed the gestational age. I would have been able to discuss the case with the nurse privately. Because the parents were present, the nurse had limited opportunities to discuss her distress with other providers. She heard the resident and me speak with the parents. She understood what was going on and knew the parents were realistic.

We reflected about the fact that we felt like a team: Domenica was more than “a 22-weeker.” She was “our patient.”

Although I was Dr Jane in this case, I am not the only Dr Jane. Most neonatologists have dealt with similar cases. I have realized through the years that who Dr Jane is matters. It matters that she is a woman. Her age matters. Doctors’ views and styles are shaped by their own experiences with previous patients and perhaps with their own children.

I work with 300 nurses in a large unit. I did my residency where I now work. Some of the nurses I work with saw me grow personally and professionally over the years. They helped me become who I am. Over the years, I shared their moral distress. When I was a resident 22 years ago, like many of them, I was morally distressed about “24-weekers.” Neonatologists listened to us, told us about the outcomes, and gave us articles, but our distress did

not decrease. Education, science, and rationality are not enough in these cases. We needed to personally see infants survive and do well. We did not need graphs, percentages, or to debrief or be listened to. Over the years, I have seen tiny infants who survive and do well. I have also seen infants survive and do badly. I also delivered preterm at 24 weeks’ gestation. Doing neonatal follow-up as a fellow gave me a lot of humility. Being in contact with families and on family social media groups helps me remain curious and humble. I see how often my prognostications turned out wrong.

Adding 1 day to Domenica’s gestational age made many providers have a different attitude about her care. It was an effective, if unprofessional, intervention. I have never repeated this; it could have had serious negative impacts in other circumstances. Since Domenica’s case, we now have dedicated support sessions for nurses that are organized by nurses. Sometimes, we do this on an emergency basis. There is still so much more to do.

Domenica had a difficult NICU course, but she survived. She is now 6 years old. Her parents are thrilled about how well she is doing. They are now family stakeholders who help us improve care, teaching, and research. With other parents, they wrote an article called “our child is not just a gestational age”²⁴ that is closely related to the case.

JOHN D. LANTOS, MD, COMMENTS

This case presents a straightforward conflict between bad policy and bad behavior. It is never good for professional morale for doctors to deceive nurses. It is never good for patients when clinicians make decisions that do not reflect the best scientific evidence and clinical judgment. In this case, a doctor was trying to do what she thought was best for her patient and her parents.

She was inhibited by many nurses' perception that such treatment was futile. These perceptions reflect a widely held but erroneous belief that treatment of babies born at 22 weeks is futile. As this case and many studies show, it is not. Decisions for babies born at 22 weeks should be made the way all good clinical decisions are made, by taking into account all the relevant clinical information and the parents' preferences then making an individualized clinical judgment.

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