OPINION

When newborn babies are dying, every minute of loving care counts

By JOHN RHEE
JAN 26, 2018 | 5:00 AM

Hanging in (janzwolinski/Getty Images/iStockphoto)

We all stood in the operating room waiting expectantly. This baby could be born with only a few minutes of life, or be vigorous and pink, or be anywhere in between. Our silence was broken only by the regular beeping of the heart-rate monitor and the obstetrician occasionally asking for surgical tools.

Suddenly, Anna was born, and a flurry of coordinated action ensued: Her photos were taken by a professional called the child life specialist; the father was allowed to hold her; she was brought to her mother to make cheek-to-cheek contact.

This past month, as part of my medical training, I rotated through the Neonatal Comfort Care Program at Morgan Stanley Children's Hospital at New York-Presbyterian Hospital Columbia working with Dr. Elvira Parravicini, a neonatologist and palliative care-trained physician.

We're all familiar with palliative care as it applies to adults — trying to reduce pain and distressing symptoms as a patient struggles with what is thought to be a terminal condition. But in that operating room, palliative care took on a totally different dimension, because it was intended to help a baby from the moment of birth and the family surrounding her.

In the United States, about 31,000 babies each year die perinatally (in the first week of life and stillbirths), and 20,000 die in the neonatal period (the first four weeks after birth).

And — likely because we're afraid of how grim the subject is — we don't think or talk often enough about the pain-relieving care these babies deserve.

I know. Even as a medical student, I expected this clinical experience at Morgan Stanley Children's Hospital to be an extremely trying, melancholy rotation. Instead, I found it to be infused with intense joy, beauty and peace.

Despite the fact that the mothers knew that their babies might not survive even a few minutes after birth, the program allowed them and the fathers to spend those moments holding, rocking and loving their child until he or she passes, experiencing the beauty of birth.

All this happens while the palliative care team does everything possible to keep the baby comfortable and interfere as little as possible in the bonding between baby and parents.

This process might be hard for many people to get their heads around. In our intensely death-aversive culture, intensive, aggressive and invasive treatment is the norm at the end of life.

And the medical community tends to want to harness all curative resources even more readily at the beginning of life — rightly so, since babies are often much more resilient and can make meaningful recoveries if stabilized quickly.

Comfort and care (TOMAS E. GASTON)

But some conditions require a different approach. And the default aggressive mentality in treating newborns often does not leave much space for frank discussion regarding when measures should be stopped or even avoided altogether.

Lending credence to this seldom-used approach, preliminary research shows that infants with life-threatening prenatal diagnoses survived the same median length of days when they received comfort care management, according to the team's guidelines, as opposed to when they received intensive care.

Such findings are important considering the collateral damage of aggressive treatment is not without its harmful effects on parents, who commonly experience mental health issues (including guilt, shame, high stress and anxiety) after putting their babies in the intensive care unit.

Having been present during many private conversations between physicians and expectant mothers, I have seen and felt the anxiety of the prenatal test, which rarely can indicate a terminal diagnosis for the baby.

And I am learning that there may be alternatives available to terminating a pregnancy. Sometimes, by allowing women to choose to carry a baby with limited time to birth by permitting a natural life course with a grieving process, mothers have a chance to better cope with their impending loss.

The Neonatal Comfort Care Program, though still in its initial stages, has shown preliminary data that parents felt very positively about how their babies were cared for soon after birth, and they had positive experiences bonding with their babies before their passing.

In the case of Anna, I spoke with her mother, who expressed deep gratitude for the care that her baby received. Despite a prenatal diagnosis of a severe brain anomaly resulting from a genetic mutation, the baby did better than any of us expected.

We should have more neonatal palliative care programs to provide this alternative to families, no matter what the prenatal diagnosis. The paradox of palliative care is that despite impending death, we can provide hope by refocusing on the present. And sometimes by intervening less, we can actually deliver better care.

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