



# Uncomfortable Comfort Care

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The author has no conflicts of interest to disclose.

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Received for publication June 6, 2019; accepted August 9, 2019.

ACADEMIC PEDIATRICS 2019;19:853–854

AT 08:00 AM Monday morning, I was called to provide an antenatal consult to Cassidy\*. This was her fourth pregnancy. At 35 and 4/7th weeks, the fetal ultrasound (US) showed multiple anomalies (microcephaly, holoprosencephaly, ventricular septal defect, bowed left femur, and possibility of caudal agenesis). Cassidy had a long history of poorly controlled type 2 diabetes with retinopathy and renal disease with superimposed severe preeclampsia during this pregnancy. I met Cassidy and introduced myself. She was lying in a propped up bed. I noted her to be in physical pain and distress but she responded to me with a smile. I presented the findings of the fetal US to her and discussed the options of care after delivery. As her obstetrician had previously explained the findings in detail, she already understood that the baby may not be able to survive for long after birth. She agreed that if her baby had severe abnormalities, the team should not offer resuscitation.

At 11:01 AM, the obstetrician delivered a female infant via cesarean section. The Apgar scores were 5 and 5 at 1 and 5 minutes and the baby was noted to have multiple congenital abnormalities. She had severe microcephaly, limb anomalies, a cardiac murmur, imperforate anus, and severe intrauterine growth restriction. In view of these and other complex anomalies, after counseling Cassidy and her family, we made a decision to provide comfort care. The baby, named Sara\*, was transferred to the nursery to room in with Cassidy.

While baby Sara was observed in the nursery, her family members raised the question of providing nutrition. With imperforate anus, an obstruction to the gastrointestinal tract, it was medically unjustified to feed her. We did not pursue surgery for imperforate anus as it will increase Sara's suffering and length of hospital stay. Cassidy did not want to prolong suffering for Sara.

Although Cassidy had agreed to comfort care, I noticed her discomfort. She started to have panic attacks; the team consulted psychiatry and initiated anxiolytics. Another

issue was her family's constant push to feed the baby making her feel guilty. They commented, "baby looks good, she is breathing... baby is hungry, feed her" and wanted Cassidy to talk to the doctors again.

At this point, we consulted social services to provide support to Cassidy and to help make hospice care arrangements. On day 2 of life, Cassidy and family members requested for Sara to be baptized and they were able to savor this private family event. On day 3, although Sara was not receiving any fluids, her heart rate remained at 120 per minutes and she was breathing spontaneously. She was discharged home with Cassidy and died there 2 days after discharge. The hospice staff informed me about her death.

During the hospitalization, I could tell it was very rough for Cassidy to go through this stressful process. She was showing signs of postpartum depression along with the complications from her long-standing diabetes. In addition, she had to deal with the terrible news that her baby would not likely survive and she had to make an end-of-life decision about her own child with multiple congenital anomalies. I could see the tears welling up her eyes, but she was trying her level best to conceal them.

Providing nutrition to infants under comfort care is a controversial subject, though most authors agree on forgoing it.<sup>1–3</sup> The dilemma for Sara was that despite being hungry, feeding her would cause abdominal distension and increase suffering. The dilemma for Cassidy was to see her baby gradually dying.

I had naively thought comfort care decisions are easy to make when treatment is considered futile, but observing Cassidy's discomfort, I realized how difficult it is for the parents. Making end-of-life decisions regarding newborn infants is heart wrenching. Parents as surrogates go through guilt on top of emotional turmoil. One positive aspect I saw was Cassidy's strength dealing with a challenging and sad situation. She was only protecting Sara. She wanted to minimize suffering and she favored the plan that she considered to be in the best interest of her daughter.

\*Names and details have been altered to protect identities.

I have to confess that it was not easy on me either. I had made the decision and guided the mother in hers, but every hour of Sara's life made me rethink whether or not I was right. Should I have called the hospital ethic committee to help? Instead I contacted 3 of my professional colleagues who practice palliative care to get their opinions. I was comforted as all told me, "You are doing the right thing." As a physician, it was surely a once-in-a-lifetime experience for me but I hope and pray that no parent should have to go through what Cassidy did. She was a powerhouse of bravery and strength. I only hope that families who find themselves enduring such a painful scenario shall have patient physicians whose care provides some comfort for uncomfortable decisions.

## ACKNOWLEDGMENTS

Newborn nursery nurses for their continuous support and passionate care provided to the Sara, Cassidy, and their family.

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