

**SEVERE ANOMALIES OF THE NEWBORN:
THE PARENTS' RIGHT TO DECIDE**

Abstract

Providers sometimes feel they are pushed to provide treatment of minimal or no potential benefit. In this case, the health care team is challenged to forego life sustaining therapy in a newly born infant with severe developmental abnormalities, a course of action that is contrary to the preferences of the parents. The medico-legal aspects of the case (including the Baby Doe regulation) are discussed.

Query

Is it ethically justifiable to forego life sustaining treatment of a newborn with severe congenital anomalies against parental desires?

CASE PRESENTATION

R.A. is a four-day old hispanic neonate male admitted to the NICU at a tertiary medical center. Shortly after delivery, he was diagnosed with multiple congenital anomalies and respiratory distress. His initial medical and nursing interventions included intravenous fluids, oxygen therapy by ventilator, frequent suctioning, laboratory studies, chest and abdominal x-rays and consultation with pediatric surgery.

Medical History

R.A. was born to a Mexican couple working in the U.S. during migrant harvests. Both parents spoke very little English and R.A.'s mother had not received prenatal care during this pregnancy. She was a 36 year old gravida 8 para 4, who reported, through the interpreter, of having no problems with her pregnancy. She further reported two previous early pregnancy losses and two babies who died within hours after their births from "bad hearts".

R.A.'s parents arrived at the hospital after advice from a family friend and his mother. She was admitted at six centimeters dilation to the Labor and Delivery Suite. The labor progressed very quickly and R.A. was delivered within the next hour. The fetal monitor tracing showed no signs of fetal distress or impending fetal problems. Due to her lack of prenatal care and reported previous neonatal deaths, the Intermediate Neonatal Care Center (INCC) staff was notified of her admission and delivery status.

R.A. was delivered by spontaneous vaginal delivery and his physical disabilities became apparent immediately at birth. The neonatal medical and nursing staff was immediately notified to attend to the newborn in the Delivery Room. R.A.'s lower extremities were fused below the umbilicus and his feet were abducted to give the appearance of a mermaid's flipper. His APGAR scores were 1 (one minute), 6 (five minutes) and 7 (ten minutes). The neonatal staff began resuscitation efforts and R.A. was intubated and bagged in preparation for transfer to the INCC.

The parents were told in Spanish that the baby was "having problems breathing" and needed to be moved immediately to the nursery. Mention of R.A.'s obvious anomalies was not made at this time and neither parent was able to view him clearly in the Delivery Room.

Upon arrival in the INCC, R.A. was intubated and pink and a thorough physical assessment was completed. The following anomalies were noted: 1) no right ear, 2) ambiguous genitalia (questionable small penis bud), 3) absent urethra or anal opening and 4) abnormal pelvis configuration with legs fused. His neurological status appeared normal with positive suck, grasp and motor reflexes. He had good muscle tone and his oxygen saturation content remained stable.

Further examination by x-ray also revealed renal agenesis and tracheoesophageal fistula. A final diagnosis of sirenomelia sequence syndrome was given. The neonatal resident returned to the labor and delivery area to speak with R.A.'s parents regarding his questionable prognosis and impending transfer to the NICU. Both parents were present during this discussion and the information was given in Spanish. R.A.'s mother

was noticeably upset and crying and his father returned to the INCC to see his infant.

After his transfer to the NICU, R.A. was examined by the pediatric surgery staff. His condition remained stable although a grave prognosis existed. It was the consensus of the neonatal and pediatric surgery teams that no further support or intervention be undertaken for R.A. Further, the decision was made to request of his parents withdrawal of the ventilator and only comfort measures be given.

The pediatric physician contacted the family on the post-partum unit and requested that both parents visit the NICU so that these decisions could be discussed. R.A.'s mother was very upset and crying, stating she could not look at the baby right now. He reassured her that he would go along and appeared very supportive to her. In the NICU, R.A. was touched and viewed by both his parents. An interpreter was present when the discussion of medical information, prognosis and suggested withdrawal of support occurred. Both parents were tearful and requested time to decide the baby's fate.

When the parents returned to the post-partum unit, R.A.'s father left to contact other family members. His mother was crying uncontrollably and related to her primary nurse that the "doctors want to kill her baby". She further stated that God would not allow her to do that and she would pray for His guidance.