Peer Reviewed

Briefly Legal: Parents Opt not to Pursue Further Surgical Treatment for their Child's Severe Congenital Heart Disease: A Nurse Threatens to Sue the Hospital, the Neonatologists, and the Parents for Withholding Care

Maureen E Sims, MD, Barry Schifrin, MD

A 34-year-old G2P1 with an unremarkable prenatal course developed premature labor at 36 weeks gestation. After an unremarkable 5 hours of labor, a male infant with a birthweight was 1800 grams (<10% percentile), a length of 41 cm (<10 percentile), and a head circumference of 27 cm (<3% percentile) was delivered at a small community hospital. The baby showed mild dysmorphic features, including low set and rotated ears and questionably small palpebral fissures. The infant was assigned Apgar scores of 8 and 8 at 1 and 5 minutes, respectively, with 2 off for color at 1 and 5 minutes. Despite supplemental oxygen, the baby's color did not improve; nevertheless. he remained vigorous and comfortable. His vital signs, including blood pressure, were normal, but his oxygen saturation persisted between 70%-85%. Pre- and post-ductal blood gases were similar and showed pO2s around 70mmHg, with normal pH and pC02 values. A bedside hyper-oxygen test did not improve his oxygen saturation. A chest radiograph showed an abnormal cardiac silhouette with extraordinarily clear lung fields – the combination of the presentation and radiographic findings pointed to a classical presentation of cyanotic cardiac disease. This presentation prompted a stat cardiac consultation, cardiac ultrasound, and the administration of prostaglandins. Shortly after the administration of standard doses of prostaglandin, the baby developed apnea, requiring intubation.

"A chest radiograph showed an abnormal cardiac silhouette with extraordinarily clear lung fields – the combination of the presentation and radiographic findings pointed to a classical presentation of cyanotic cardiac disease."

The cardiac ultrasound revealed a severe variant of Tetralogy of Fallot. A complete blood count (CBC) and a metabolic panel were normal. The cardiologist recommended operative treatment in several stages. Neuroimaging with ultrasound, computerized axial tomography (CT), and later brain magnetic resonance imaging (MRI) were interpreted as normal. The genetic consultation agreed with the dysmorphic findings, but all laboratory evaluations were normal. These investigations were carried out with ongoing updates and discussions with the parents by the neonatologist, who found them to be concerned and available. With each intervention, he encouraged open questions. At their first encounter, he explained to the parents some of the uncertainty of even advanced medical procedures. He shared with the parents that sometimes, neonatologists might get mired in the details of the procedure at hand and lose sight of the "big picture." In this framework, he invited the parents to question him and his colleagues whenever they felt that the medical team was not seeing the "big picture." Both parents worked in the medical field and had an excellent grasp of the benefits, risks, and alternatives of the procedures. The father was a respiratory therapist at a cancer facility, and the mother was a laboratory technician at the birth hospital. They consented to the first cardiac surgical intervention.

"He shared with the parents that sometimes, neonatologists might get mired in the details of the procedure at hand and lose sight of the "big picture."In this framework, he invited the parents to question him and his colleagues whenever they felt that the medical team was not seeing the "big picture.""

After undergoing phase 1 of surgical intervention, the 8-week-old baby continued to have heart failure, and despite maximum nutritional intervention, restricted fluid intake, and diuretics, he could not be extubated. Further, the baby had a very shallow growth curve; the head circumference showed minimal growth from the measurements at birth. After another month, the cardiologist recommended the 2nd phase of the cardiac surgical procedure in the hope of improving the cardiac failure. As the neonatologist was discussing the need for a second surgery with the parents, the parents expressed their concern that the overall picture appeared bleak in terms of ultimate prognosis and the quality of life of their son; they were considering not putting their child through another surgery. The neonatologist did not expect this reaction but appreciated and understood their challenge. The parents expressed their love for the child but that they felt it was in his best interest not to have another surgical procedure and to remove the endotracheal tube and let nature take its course. After much discussion with the nurses, respiratory therapists, cardiologists, and neonatologists agreed to extubate the baby and provide only comfort care. They would not reintubate, irrespective of apnea or further deterioration.

"The parents expressed their love for the child but that they felt it was in his best interest not to have another surgical procedure and to remove the endotracheal tube and let nature take its course. After much discussion with the nurses, respiratory therapists, cardiologists, and neonatologists agreed to extubate the baby and provide only comfort care."

"All the nurses agreed to this approach except one, who stated that withholding care was against her religious beliefs... The cardiologist also did not agree with the parents and neonatologist's plan. He pointed out that despite the potential for severe cognitive impairment in the baby, he thought that further surgical procedures were warranted."

All the nurses agreed to this approach except one, who stated that withholding care was against her religious beliefs. She was reassured that she would not be assigned to the baby and was not asked to provide any care for him. Most of the nurses in this hospital had worked at major university medical centers, and some had worked in institutions where children received chronic care. The one nurse who strongly disagreed with the plan of extubating and comfort care called the parents at home in an attempt to convince them to reconsider. Despite advising that she would not pursue the matter, she persisted. The cardiologist also did not agree with the parents and neonatologist's plan. He pointed out that despite the potential for severe cognitive impairment in the baby, he thought that further surgical procedures were warranted. The neonatologist assured the parents that, if necessary, arrangements could be made to send the baby to a University or Childrens' hospital where their wishes would be honored. The neonatologist had presented the details to a colleague at another facility, who agreed with the plan and who gave assurances of following the same course. The parents preferred to stay at the birthing hospital and have their wishes followed.

"The parents emphasized their love for the baby and that they felt it was in their baby's best interest to let nature take its course without a ventilator and allow him to feed as he could."

At the parents' request. a Bioethics Committee meeting was convened. At the meeting, representatives from nursing, medicine, administration, community and clergy, the parents, and the neonatologists were present. The parents understood that the Committee meeting was a venue to sort out issues and was not a decision-making body, that they had the right to make the decisions for their child, and that the neonatologists were responsible for practicing within appropriate standards of care. At the Committee meeting, the neonatologist voiced his opinion that the parents are considered the best decision-makers for their babies and should be involved in shared decision-making whenever possible. For parents to fulfill this responsibility, they needed relevant, accurate, and honest information about the risks and benefits of each treatment option. The neonatologist felt that the parents, with their medical background, had been fully informed and given adequate time to consider the options and ask questions thoughtfully. The parents emphasized their love for the baby and that they felt it was in their baby's best interest to let nature take its course without a ventilator and allow him to feed as he could. They wanted to hold him and allow their other child, who was eight years old, to be present. Half of the Committee members favored more intervention, with one suggesting a judicial process (obtaining a court order) be initiated if needed. The neonatologist pointed out that if a judicial process were set into motion, the baby would be transported to another facility that would honor the plan the neonatologist and parents had outlined (comfort care). After the father spoke to the Committee members, all agreed with the comfort care plan. The neonatal care nurse who was opposed (not present at the meeting) informed the hospital that she would be contracting an attorney and the press. The hospital was concerned about a conflict of interest since the mother's health insurance was through the hospital where she was an employee; the hospital administration asked for a consult from the Chair of the local Children's Hospital. He consulted and agreed with the plan agreed upon by the neonatologist and parents.

"The baby and his family were provided privacy in a separate room near the NICU. The baby was extubated and expired 18 hours later in his mother's embrace."

The baby and his family were provided privacy in a separate room near the NICU. The baby was extubated and expired 18 hours later in his mother's embrace. The nurse who opposed this plan failed to obtain an attorney willing to take on this case, and nothing was published in the press. Weeks later, the mother contacted the neonatologist and said she would be willing to help support other parents faced with similar situations but decided to resign from her employment at the hospital because of the painful memories of the badgering and the threats of the nurse.

Suggested Reading:

1. Pineda R, Neil J, Dierker D, et al. Alterations in brain struc1. AAP Committee on Bioethics. Informed Consent, Parental Permission and Assent in Pediatric Practice. Pediatrics 1995;95 (2) 314-317
2. Committee on Bioethics. Informed consent in decision-making in pediatric practice. Pediatrics 2016 138:e20161484
3. Guidance on Forgoing Life-Sustaining Medical Treatment Policy Statement AAP Weise, K, Okun AL, Carter BS et al. Committee on Bioethics, section on hospice and palliative medicine, Committee on child abuse and neglect Pediatrics 2017; 140: 2017 e20171995
4. Wasserman JA, Navin MC, Vercler CJ Pediatric Assent and Treating Children Over Objection Pediatrics 2019; 144 (5) e20190382
5. Wyckoff MH, Wyllie J, Aziz K, et al. 2020 International Consensus on Cardiopulmonary Resuscitation and Emergency Cardiovascular Care Science with Treatment Recommendations. Circulation 2020 142 (suppl 1) s185-S221

Disclosures: *There are no reported disclosures*

NT

Corresponding Author

Maureen E. Sims, M.D.
Professor of Pediatrics
Geffen School of Medicine
University of California, Los Angeles
Los Angeles, California
email: mes@g.ucla.edu

Barry Schifrin, M.D.
Western University of Health Sciences
Pomona, California
formerly, Professor of Obstetrics and Gynecology
Keck School of Medicine
University of Southern California
Los Angeles, California