

PROFESSIONAL VIEWPOINT: Journal Club

By: John C. Carey, MD, MPH, Medical Advisor, SOFT

Boss RD, Holmes KW, Alphaus J, Rushton CH, McNee H, McNee T. 2013

Trisomy 18 and Complex Congenital Heart Disease: Seeking the Threshold Benefit. *Pediatrics* 132:161-165.

This interesting paper is the latest piece included in the relatively new section in the journal *Pediatrics* under the heading of "Ethics Rounds." Two years ago I reviewed another contribution to "Ethics Rounds" in *Pediatrics* (in fact the inaugural paper in this new series instituted by the journal). In this recent paper, the authors present the case study of a fetus diagnosed with trisomy 18 and a complex congenital heart malformation consisting of a double outlet right ventricle. This particular heart defect is a serious and complicated one regardless of any overall syndrome diagnosis. The parents in this case "requested any maternal or neonatal interventions be performed that could extend their daughter's life." The parents specifically requested that the trisomy 18 diagnosis not be included in the decision making about their daughter. Of note, the parents in this case study are co-authors on the paper. The story evolved in a notable way, as some of the clinicians did not feel that they were able to participate in the maternal or neonatal interventions because they felt that the burdens of these interventions outweighed their benefits. Because of this conflict, an ethics consultation was requested for "additional guidance."

The paper proceeds with discussing the response of the fetal medicine team and the comments of the parents. The paper then summarizes the conclusions of the ethics committee, and Dr. John Lantos, a pediatrician and medical ethicist comments to close the piece. Some of the members of the perinatal team felt that life-sustaining intervention "would only prolong the dying process." These members of the team recommended "palliative care only." The parents believed that surgery was in their daughter's best interest. Some of the doctors on the team advocated that since there was some chance of survival that surgery was "consistent with the parents' values." As mentioned, the ethics committee of the hospital was convened. They interpreted the conflict as one between "a desire to respect the parents' wishes and the individual clinician to act on his or her conscience." One of the issues that emerged from the discussion of the ethics committee was whether or not it was appropriate to transfer care to another facility. The ethics committee and team agreed that it would have been difficult to transfer care because of the discussion that already had occurred. Of note, the paper points out that there is a complexity here in balancing the "clinician's right to refrain from patient care that he or she finds mildly objectionable with the burden posed by the patient having to seek care elsewhere." The committee and team resolved this issue by agreeing to care for the patient at their institution but also to schedule "nonobjecting" staff to be scheduled to accommodate the parents' care plan.

At term and before delivery, the baby died in utero. The family then chose to return home for delivery by their own obstetrician.

This case raised a number of issues, many of which were already discussed in the Ethics Rounds of 2011. These issues include accurate data regarding outcome quality of life, parent autonomy, and the

potential suffering of the child. Two issues struck me as being more unique in this case, however: The fact that there was an open discussion of possibly transferring care (and the ethics committee and team decided against this) and the issue of some clinicians finding it themselves against their conscience to be involved in the care. Dr. Lantos's closing comment – I would suggest – goes to the essence of the issue and summarizes my own view (and one stated by others in recent years regarding this conflict):

"Given the data, decisions about...to pursue life-sustaining treatment or to choose palliative care after birth for infants with trisomy 13 or 18 should clearly be made by fully informed parents." There are a number of key concepts in Dr. Lantos's comments: "The data," "fully informed parents."

I applaud Pediatrics, the most prestigious and high impact journal in the field, continuing to facilitate the dialog with publications in the "Ethics Rounds." I look forward to continued discussion of the topic, especially around decision making regarding heart surgery.