Whose Interests Count?

The Arnold P. Gold Foundation Ethics for Lunch Seminar Series

A Difficult Case from the Morgan Stanley Children’s Hospital Ethics Committee

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The Ethics for Lunch presentation began as Dr. Ruth Fischbach, Director of the Center for Bioethics at Columbia University, greeted the audience and thanked Drs. Arnold and Sandra Gold for their nine years of generosity that have made the Ethics for Lunch events possible. The Gold Foundation is committed to promoting humanism in medicine.

The case confronted in this session is a particularly troubling and poignant ethical dilemma as Dr. Fischbach noted in her introduction. What could be more sad and troubling than having a very young infant with severe illness or disability that threatens its very life and certainly its quality of life? And while we may have the technology to save the baby, there are many considerations that must be attended to. The technological imperative states that if the technology exists, use it. But perhaps more important is the ethical imperative that states – it’s not what you can do, it’s what you should do. So what should you do in this case?

There are many rights and interests to keep in mind – not the least of all the infant’s. But then you should consider the interests and rights of the parents’, the physicians’, the hospitals and even the states’. And by the way, don’t forget the interests and rights of the siblings and other family members. How much burden is it fair to impose on them? And on what basis do you make your decision whether to provide aggressive or comfort care to this infant? You could consider the infant’s best interests, the expected quality of life, and the medical approaches that are feasible. But soon you have to decide whose interests trump all others and whether it may be ethical for the parents to decide to withhold treatment and opt for comfort care only.

Dr. Fischbach then introduced the speaker, Dr. George Hardart, who is the Director of Pediatric Clinical Bioethics for the Center for Bioethics and an Associate Clinical Professor of Pediatrics, and Director of the Children’s Hospital of New York (CHONY) Consult Service. Furthermore, he is a compassionate physician in the Division of Pediatric Critical Care Medicine at CHONY and serves on both the CHONY and the Columbia University Medical Center’s Ethics Committees.

Dr. Hardart described the case for the day: Jenny (not her real name), a three-week old infant with Atrial Septal Defect, Ventricular Septal Defect, and Patent Ductus Arteriosus was brought to the hospital for heart surgeries. The baby had previously suffered from sepsis and was in critical condition, requiring intubation and mechanical ventilation as well as potent medication. After some time of hospitalization, her condition improved; her medications were switched to oral heart strengthening medications, and she was put on noninvasive ventilation. The heart surgery she was to receive was semi-routine with a high success rate. Before scheduling the surgery, doctors identified some dysmorphic features and so ordered genetic testing. The results revealed a rare genetic mutation that would leave the child with cognitive impairment similar or more severe to that of Down’s syndrome. After this information was presented to the parents, they refused to have the surgery and the medical team was faced with a
dilemma: to abide by the parent’s wishes or to perform the heart surgery against the parent’s decision by taking the baby’s case to court. Without the surgery the baby would suffer greatly with a short life expectancy, but successful heart surgeries to correct the three heart deformities would still leave her with mental impairment, which the parents feared.

Dr. Hardart proceeded with the ethical challenges presented in this situation: in the case of pediatric patients who are deemed incompetent to make medical decisions on their own behalf, who should have a say in the decisions regarding their health?

For pediatric patients who have never been competent, the governing principle for their treatment is to do what is in the patient’s best interest. Respecting the principles of beneficence and non-maleficence, the burdens and benefits of each treatment is to be weighed objectively for the patient’s best outcome. It is often the parents of the child who have the power to make medical decisions, but despite the belief that parents are apt to make choices for their child’s best interests, it is sometimes not the case.

Parents can be conflicted with other values that clash with their child’s best interest, be it their marriage, family goals, financial implications, or concerns for other siblings. Their values are not individual centered, and this leads to the ‘rivalry of care’ in which morality of medicine (best interests for the patient) is in conflict with morality of family. As a result, the parents’ autonomy may be constrained. For instance, the reasons stated by Jenny’s mother’s refusal for treatment were fears of the severe impact that Jenny’s disability would have on her marriage and on the other children.

Despite this conflict of interest, Dr. Hardart remarked that for pediatricians, incorporating family interests is an important part of the job. According to a survey of physicians in pediatric and neonatal intensive care, the majority contend that family interest is often tied intricately with medical decisions for young patients. It is clear that there are lines that should not be crossed even with the family’s wishes, such as withholding treatment for a newborn’s survival unless it is deemed futile (Baby Doe Law). However, constant efforts to weigh a treatment’s benefits and burdens along with other indicators such as the child’s functioning, quality of life, prognosis, life expectancy, and family interests also should be sustained.

This case captures how such efforts lead to optimal outcomes: physicians were aware of the shock that the parents were going through with the new information of the genetic mutation and so provided them with ample time to carefully consider their decision. They also tried to alleviate the father’s misconception: Jenny’s condition was not ‘terminal’, and the severity of cognitive impairment could not be determined with certainty.

In the end, the parents were persuaded to continue with the surgeries, and Jenny is now a happy three-year old with mild to moderate cognitive deficits. Importantly, the parents are at peace with their decision.