
UNIVERSITY OF MIAMI SCHOOL OF MEDICINE

MASTERS OF PEDIATRICS

BIOETHICS WORKSHOP

Faculty

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1. Introduction

This workshop aims to provide a case-based overview of some leading issues in pediatric bioethics. A key goal of the workshop is to illustrate strategies for bioethical decision making in real-world cases. Participants will join in roundtable discussions of cases presented in this workshop syllabus. The cases are drawn from ethics consultations sought and received at the University of Miami/Jackson Memorial Medical Center.

All the cases are actual; none has been altered or invented. Each case appears under a particular heading. This approach is useful in identifying (what is arguably) the most salient issue raised by the case, but it should not be viewed over-rigidly: most cases raise an ensemble of issues and it is difficult to reveal all conceptual anastomoses. For instance, many or most "brain death" cases will raise issues of terminating or withholding treatment. In any event, the headings are far from exhaustive.

Additionally, participants will be able to present cases from their own experience for discussion in the small-group sessions. The section titled "Health Care Reform: Economics and Responsibility" explicitly calls for such contributions by participants.

The workshop faculty comprises a physician (Holzman), a psychologist (Armstrong) and a philosopher (Goodman). All are members of the Pediatric Bioethics Committee at the University of Miami/Jackson Memorial Medical Center.

2. Surrogacy

Case: A 10-year-old male on mechanical ventilation is in a persistent vegetative state secondary to several cardiopulmonary arrests and prolonged periods of low blood pressure. His neurological function is at a low brain stem level, including only occasionally reacting pupils and occasionally spontaneous breathing. There has been no significant change in neurological status since admission two weeks earlier. The intermittent pupillary and respiratory activity preclude a diagnosis of brain death.

The patient is in the custody of Health and Rehabilitative Services. His mother died six months ago and no information is available about his father. An aged aunt and 18-year-old brother had been caring for the child, but the aunt was unable to provide needed care. They have been visiting the patient and remain involved, however. Nevertheless, they are not his legal guardians and consent for treatment must be obtained from HRS.

The attending physician recommended that mechanical ventilation be withdrawn because the patient is in an irreversible coma from which there will be no recovery. The aunt, brother and HRS caseworker support such withdrawal and understand that it will likely and shortly lead to cardiopulmonary cessation. The HRS supervisor has been contacted,

but informed the team that HRS is prohibited by law from making decisions about withdrawal of care.

Keywords: brain death, futility, legal petitions, surrogacy

3. Withdrawing, Withholding and Refusing Treatment

Case: A 17-year-old male (17 years, 48 weeks) with massive Ewing's sarcoma of the pelvis that is invading the femoral head. There is abdominal compression and elevation of the diaphragm that has resulted in respiratory distress; the patient was placed on mechanical ventilation about a month ago. The patient has received chemotherapy with some reduction in tumor size, but substantial residual mass remains. A second course of chemotherapy did not affect tumor mass. There is also a question of a pulmonary metastasis that has not been completely evaluated. The patient was placed on a mechanical ventilator because of persistent metabolic acidosis and increased work of breathing. He was subsequently made a DNR because if he progressed to a cardiac arrest it would indicate that his overall disease had advanced to the point where further care would be futile.

Additionally, further treatment for his primary disease, if possible, would include some combination of surgery (hemipelvectomy), chemotherapy and/or radiation therapy. Before the need for intubation, treatment options were discussed by the patient, his mother and the staff. The patient said he desired aggressive therapy. Some staffers believe, however, that the patient took this stance out of a sense of obligation to protect and support his mother.

The patient's social situation is difficult. His family consists of his mother and sister; his biological father left the family when the patient was 2 and has not been heard from since. At the time the diagnosis was made, the family was in the process of moving to New Jersey, and because of a dispute between the mother and sister, the Miami home is unstable. The patient's mother has been assessed by staff as being impaired in her ability to provide him with meaningful support. Indeed, on a number of occasions the patient has had to provide emotional support for his mother. The mother has indicated she wants care withdrawn, but has vacillated in this request.

Keywords: DNR, family conflict, futility, informed consent by minors

4. Fear of Litigation or Liability

Case: An infant is born at 38 weeks of gestation (4,405g) by C-section at a community hospital. An abdominal ultrasound performed for breech presentation had shown macrocephaly. This condition was diagnosed just before delivery; ultrasound at 3 months gestation was unremarkable. Physical examination showed typical findings of massive hydrocephalus.

Parents are adamant that the infant receive no feedings or treatment. Risk managers and physicians at the community hospital were reluctant to comply with the parents' wishes, fearing legal ramifications; they insist on tube feedings.

The day after birth, the infant is transferred to the university medical center, where physicians confirm the diagnosis of hydrocephaly and conclude that any treatment and feeding would be inappropriate. None is given.

Keywords: fear of litigation or liability; role of academic medical centers

5. Organ Procurement, Donation and Transplantation

Case: The patient is a 2-year-old male with Arnold Chiari malformations, myelomeningocele repair and hydrocephalus with a VA shunt. The patient was admitted to the PICU in transfer from a local emergency department, where he had been brought when found lethargic and difficult to arouse. The patient was noted in the ED to be bradycardic and bradypneic; at the PICU the patient had a GCS of 4 and subsequent EEG was consistent with brain death. The parents approached the medical staff to inquire about consenting to organ donations, saying they did not want their child's death to be "wasted." However, when an apnea test was performed, the patient had spontaneous respirations. A blood-flow study of the cranial vault revealed a persistent flow, although it was thought that this might have been facilitated by the VA shunt. Over the next days a degree of brain stem function returned. Clinical status has been static for about one week.

The parents are medically sophisticated, involved and articulate. They had been approached about withdrawing care, but said they could not cope with authorizing such an action. They also expressed ambivalence in that they said they wanted their child to be resuscitated were an arrest to occur.

Also: The parents are aware there is a child in the unit awaiting organ donations. It is not known if this fact has influenced them.

Keywords: brain death, organ donation, organ procurement, parental inconsistency

6. Professional Conflicts Among Health Care Workers

Case: An 8-month-old female born at gestational age of 23 weeks and weighing 540 grams. The patient initially suffered from hyaline membrane disease and was treated with surfactant and mechanical ventilation. A patent ductus arteriosus was diagnosed at about 2 months and treated with indomethacin and surgical ligation. A Grade 4 intraventricular hemorrhage occurred, but did not require initial intervention. Complications of treatment included rickets with multiple bone fractures as late as 6 months and nephrocalcinosis. The patient's most significant medical problem now is chronic lung disease complicated by cor pulmonale. She was weaned to room air but developed a constant oxygen requirement of 30% to 60%. Echocardiograms as early as 2 months documented pulmonary hypertension and cor pulmonale. She has been treated with significant fluid restriction, multiple diuretics at high doses, aerosolized bronchodilators, systemic steroids and digoxin.

She now breathes 60-80 times per minute. She has moderate retractions and expiratory grunting. She is very "short of breath" and does not tolerate activity or sitting up. Her chest seems underdeveloped in relation to weight and length. Her resting heart rate is about 170.

The patient is severely impaired neurologically. She has hydrocephalus with continuing enlargement of lateral, third and fourth ventricles. She receives weekly lumbar punctures to remove CSF. She developed generalized seizures while on aminophylline and now is on maintenance phenobarbital. She has no head control or purposeful movements, and does not smile or vocalize; she has been determined to be cortically blind by ophthalmological examination. She responds to pain with crying and has normal cranial nerve function. Her corrected age is 4 months.

The patient's mother has been diagnosed as HIV positive and is a recovering cocaine abuser. She is very involved with the patient's life and wants to care for her at home in the future. She is up to date on her daughter's diagnosis and condition.

The patient's ELISA has been negative and her T-cell counts are normal. However, she has oral thrush resistant to treatment.

At 7 months, the patient developed bronchospasm and pulmonary edema, requiring treatment with aminophylline drip, systemic steroids, frequent aerosolized bronchodilators and extra diuretics. Her PCO₂ rose from 60's baseline to high 90's. O₂ requirement rose to 80%. The situation was discussed with the patient's mother over several days by three different physicians. It was the belief of the unit physicians that the development of bronchospasm and pulmonary edema (in the absence of signs of upper-respiratory infection or other precipitating event) represented a continuing deterioration of the baby's chronic lung disease; a decision was then made not to place the baby on a ventilator. This was in accord with the mother's wishes: she viewed ventilator therapy as "cruel" in that it would not improve the baby's long-term prognosis, which the treating physicians see as bleak and most likely terminal.

However, there emerged a disagreement among the neonatal attendings about the decision not to ventilate the patient—some suggested there was insufficient certainty about the patient’s purportedly bleak status. Specifically, some members of the team (nights and weekends on call) objected that they were being asked to carry out a plan without having been involved with discussions leading to formation of the plan.

In the meantime, the patient is on a 35% O₂; the aminophylline drip was discontinued; efforts to wean her from the steroids have been unsuccessful.

Keywords: futility, professional conflict, uncertainty

7. Health Care Reform: Economics and Responsibility

Participants are encouraged to present cases illustrating changes in clinical pediatric practice caused by health care reform. In small-group discussions, the ethical aspects of such changes will be explored and analyzed.