Clinical Ethics Dilemmas: Experiencing Differences Between European and American End-of-Life Care

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Editor?s Note: This column presents a problematic case that poses a medical-ethical dilemma for patients, families, and healthcare professionals. As it is based on a real situation, some details have been changed in the effort to maintain confidentiality. In this case, the medical community is unaware of the treatment plan recommended by a foreign physician.  

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Question:  
An American mother no longer wishes to care for her handicapped child. Should the American system allow a European-trained physician to address euthanasia for the purpose of organ
Case Presentation
A four-year-old girl with severe medical disabilities was admitted to the hospital under the care of a neurologist who had immigrated to the United States after receiving his training in Europe.

After an uncomplicated pregnancy and vaginal delivery, the child was born with lissencephaly and cerebral palsy in addition to being blind and deaf. Her neurological deficits were severe, and she required the placement of a ventricular-peritoneal shunt. She had both petit mal and grand mal seizures and required feedings through a gastrostomy tube. Over the subsequent years, she required numerous hospital admissions for aspiration pneumonias and various viral infections. In addition, she had developed chronic muscular spasms from the cerebral palsy that were reasonably well-controlled with medications. At two and half years, she required placement of a tracheostomy with oxygen supplementation prior to discharge, because of persistent respiratory distress. The child?s mother, having expected that the tracheostomy and oxygen would have helped the child more, was now disappointed that the respiratory condition appeared unlikely to improve.

During the prior four years, the girl?s single mother had received substantial home care services. The week prior to this admission, these services were withdrawn because of lack of continued external funding. The mother was distraught, as she had no other caregiver support. As home services were ending, the patient?s mother petitioned a particular neurologist for assistance in the withdrawal of life-sustaining care from her daughter. The physician suggested admission to the hospital with the explicit intent of withdrawal of medical care and organ donation. Subsequently, he proceeded to provide the mother with handwritten orders for his recommendation of medical treatment, and admission was planned for the day that he was scheduled to return from a previously planned trip to Europe.

On admission to the hospital, a medical-pediatric resident examined the patient and obtained the pertinent medical history from the child?s mother. The resident, who had cared for the child during prior hospital admissions, found nothing by history or physical examination that was substantially different from prior exams. In particular, the neurological exam revealed the same global deficits as previously noted, and the child did not appear to be in any pain. The resident?s examination did not reveal any new acute medical process or any deterioration in the ongoing chronic medical condition. During the admission process, the child?s mother presented the orders from the neurologist to the medical resident.

The resident had serious reservations about the content of the medical orders and attempted to call the neurologist. When the admitting attending physician could not be reached, the resident subsequently contacted the Pediatric Residency Program Director, and an Ethics Consultation was requested.

Denouement
As the physical condition of the child was essentially the same as during prior hospitalizations, the child was provided with comfort care, and there was no clinical deterioration in the child?s condition. When the attending neurologist returned, he initially scolded the resident for not following his orders. However, after subsequent conversations with another pediatric attending
physician, he acknowledged that he had not fully understood the "living donor" protocol, and he concurred that the patient did not meet such criteria. The child's mother informed the neurologist that she did not want to take her child home, and they met privately. Subsequently, the physician prescribed a single fentanyl patch for pain and then discharged the child to terminal home care. The dose exceeded the routinely recommended dose for pain but was in the upper limits of the acceptable dosing range when taking into account the prior use of narcotic medications in the patient. The child died at home forty-eight hours later with only her mother present. There was no autopsy or drug screening. The child was cremated immediately. The discharge summary, dictated by the neurologist, was inconsistent with the chronic stable medical condition that was documented on the admitting history and physical done at the time of the child's last hospital admission.

**Comments by Dr. Rutecki**
The medical community in which this case occurred is learning to amplify its ethical interface with hospital staff. Ethics Committee and consultation activities have been relatively recent and limited in scope. Over time, further efforts in cases like this one may include education aimed at the "Dead Donor Rule," the Law and Euthanasia, as well as differences between European and American contemporary practices in this important area. Also, although Ethics Committees and Consultants should not be viewed as "policemen," the mother and neurologist's home care for this child should have been supervised, particularly in regard to pain medications and their potential to adversely affect breathing. If concern persists in regard to the neurologist, future charts should be audited to ensure compliance with United States law and health care practice.

**Editor's Comment**
It is not unusual for physicians to have distinctly different approaches to a specific medical issue. So long as there is no violation of the standard of medical practice within the medical community, this is often referred to as the "art of medicine." If such a violation occurs, there may well be medical-legal consequences. Physicians are medical emissaries who need to be aware of the nuances of the country and medical community of which they are a part.

*Editor's Note: This essay, used by permission, originally appeared in Ethics & Medicine: An International Journal of Bioethics 28(2), Summer 2012, 77-79.*