

CASE #1

CONSIDERATION OF WITHDRAWAL OF GASTROSTOMY FEEDINGS IN A PATIENT WITH PERSISTENT VEGETATIVE STATE

CASE PRESENTATION

Complaint

The patient is a 19-year-old male in a persistent vegetative state (PVS) for 13 years whose parents have requested consultation to help in the withdrawal of gastrostomy tube feeding.

Medical History

The patient was in good health until 1977 when, at age 6, he suffered accidental near-drowning. He was under water for approximately 6 minutes. Cardiopulmonary resuscitation including 5 electrical defibrillations over 45 minutes was successful in restoring an effective spontaneous cardiac rhythm. The patient required mechanical ventilation for the first 4 days and then was discontinued because of adequate spontaneous ventilation. Tracheostomy was performed to help in the management of airway secretions. Immediately after the near-drowning event and during his few weeks hospitalization, the patient was described by the physicians as "comatose, totally unresponsive to his environment". Percutaneous gastrostomy tube was placed to provide fluids and nutrition. Further details regarding the initial hospital stay are not available from family, deceased prior attending physician or medical records.

After hospital stabilization, the patient was discharged home in the care of his parents. Within the first year the patient had further medical evaluation and treatment including: 1) newly available CT head scan which demonstrated severe brain injury, 2) air transport to Houston, Texas for treatment with a new medication in hopes of restoring neurologic functioning, and 3) a trial of treatments prescribed by a researcher in Japan. Despite these efforts the patient remained unchanged and in 1978 was admitted to a long-term care facility for children. He required daily skilled nursing care and intermittent treatment for respiratory and urinary tract infections and decubitus ulcers. In March 1988, the patient was transferred to an adult nursing facility. His physician and nurses for the past 21 months indicate that the patient is medically stable. He is totally bed-bound. He does not respond to voice or tactile stimulus except with occasional moaning or withdrawal posturing. His eyes are open, do not track and require frequent lubrication. Oral care is required three times daily due to gingival hyperplasia from chronic phenytoin therapy. Tracheostomy suctioning is needed every 1 to 4 hours. Position change is done every 2 hours to prevent decubitus ulcers. Despite ongoing frequent physical therapy, the patient has developed severe joint contractures. His medications include therapeutic phenytoin for treatment of well-controlled seizures and diazepam used intermittently for control of spasms.

On physical examination the patient was supine, unresponsive to verbal and tactile stimuli. Vital signs were normal, his weight was 77 lbs. There was no visual tracking. The

gingiva were hypertrophied and tracheostomy site was well-healed. The chest had scattered rhonchi and the heart was normal. The abdomen had normal bowel sounds, epigastric percutaneous gastrostomy tube, and was soft without organomegaly or masses. There were severe contractures of the wrists and ankles.

Diagnosis

Prior and present attending physicians have diagnosed PVS based on 13 years of clinical observation. No reversible causes of the patient's decreased mental status are present.

Social History

The patient is the third of three boys in a Protestant family. The parents relate no unusual family difficulties prior to the patient's accident. During the first year at home after hospital discharge, the older brothers developed behavioral problems, the parents separated (and later divorced) and family financial resources were depleted. The family problems, the failure of medical treatments and stresses induced by negative media attention prompted the patient's admission to the pediatric nursing facility. The parents visited the child three times each week and were pleased with the quality of care. Their relationship with the patient is described as very caring by the physician and nurses. In March, 1988, the parents decided to request withdrawal of gastrostomy tube feeding because of their better understanding of PVS and acceptance of their son's prognosis. The withdrawal request is consistent and supported by all immediate family members who believe that this is the most loving thing that can be done for the patient.