Case #5

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Case Presentation

A 55 year old male suffered a subarachnoid hemorrhage from ruptured cerebral aneurysm. His treatment in the acute care hospital included coiling of the aneurysm by interventional radiology and removal of the hematoma by neurosurgery. Despite critical care support he remained unresponsive. The patient's wife, who had the medical power of attorney, decided to withdraw support after seven days in the intensive care unit based on the patient's expressed values that he would not want to live in a vegetative state and that quality of life was very important to him. He was removed from the ventilator and other critical care support was stopped. The patient continued to breathe on his own and was transferred to an inpatient hospice unit. After two days on the inpatient hospice unit, the wife asked the doctor to accelerate the death process as she was ready for her husband to die and did not want to wait any longer. She believed he would be distressed to be living like this. She stated that the neurosurgeon had told her the patient would die within a day of withdrawal of the ventilator and she did not understand why he was still alive.

This case leads into a discussion of the ethical principles of beneficence (doing good), nonmaleficence (first, do no harm) and autonomy. The hospice team should be able to assure that the patient is comfortable (beneficence) based on the appearance of the patient and nonverbal signs of distress, such as grimacing, sweating, tachycardia or elevated blood pressure. Also, any signs of respiratory distress should prompt therapy to relieve that distress and/or manage airway secretions. The hospice nurses should be able to judge the patient's comfort and treat accordingly. The wife may be a better judge of his appearance based on her knowledge of his prior pain-related behavior; however, some families actually may be poor judges of comfort because they believe their family member is a complainer with poor pain tolerance, or they say the patient "always looks like that."

The combination of the assessment of an experienced nurse and the family's assessment is probably the best judge of patient comfort. If the wife is genuinely concerned that her husband is in distress, it would be appropriate to address discomfort by any means necessary. The goal of the hospice team should be to relieve suffering and titration of medications is based on comfort, not ending life. The hospice team should discuss their own comfort level with the treatment they are providing and assure that they are actually treating the patient and not the wife's anxiety.

In this case, since the patient is unresponsive, escalating opiates and benzodiazepines to the point of death would be a clear violation of the principle of nonmaleficence, essentially euthanasia. It also would be a violation of law in this country. States that allow physician-assisted suicide require a patient with full capacity to request termination of life. Additionally, this would not be a case of palliative sedation since the patient is not expressing the distress himself. (For discussion of palliative sedation see reference listed below.)

In this setting it is appropriate to assure comfort as best as possible and to discuss with the wife the uncertainty of prognosis. Pastoral care also can be a good resource to address spiritual distress of the family. Occasionally, when the patient lives longer than the family expects after life support is withdrawn, the family will second guess the diagnosis and second guess the decision to withdraw support to the point of considering restarting aggressive life support. They ask themselves and the hospice doctor, "Did we do the right thing?" Continued reassurance of the terminal diagnosis and poor prognosis for recovery of quality of life, hopefully, will help the family through this difficult situation. Also, the hospice team can remind families that doctors are never perfect at predicting time of death.

The hospice team should keep the focus on the patient and what he would want (autonomy). The MPOA should be making decisions based on what she thinks the patient would want. Of course, it may be impossible to separate her feelings and anxieties from the decision process. Sometimes, while one family member wants to accelerate the death process, others may appreciate the time to say final goodbyes. In this case, the patient's sister appreciated the extra time to prepare for the death and felt that the patient appeared comfortable.

The nurses and hospice physician examined the patient frequently and continued to treat any apparent discomfort and the patient died after five days on the inpatient hospice unit, 12 days after the acute event. Chaplains, nurses and other family members helped comfort the wife and the hospice team will continue to provide bereavement support for one year following his death.

References:

Quill TE, Bernard L, Brock DW, Meisel A. Last Resort Options for Palliative Sedation, *Ann Intern Med* 2009;151: 421-424.

Walsh D. Palliative Medicine 1st ed. Chapter 18: Ethics and Clinical Practice. Saunders 2008.

Resource for families facing end-of-life decisions:

Dunn H. Hard Choices For Loving People: CPR, artificial feeding, comfort care, and the patient with a life-threatening illness. 4th ed. A& A Publishers Inc. 2001. *www.hardchoices.com*.