



Ethical Principles in Action:

Autonomy, Veracity, and Justice...Oh My!

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Case: GW is a 40 year old male veteran who was diagnosed with ALS in 2007 and was admitted to VA Home Based Primary Care (HBPC) in February 2009. He lives at home and his primary caregiver is his mother. Upon admission to HBPC, GW had a computerized eye gaze device for communication and could communicate clearly. He was having increased difficulty swallowing with obvious aspiration and shortness of breath. Because of clear signs of rapid deterioration, multiple providers discussed his care preferences with him and his mother. By July 2009, he had lost a significant amount of weight and had become quite debilitated. The HBPC staff wanted to send him to the hospital for evaluation but he refused. Due to increased weakness and severe discomfort, GW eventually agreed to go to the Emergency Department.

GW went to the ED to be evaluated, but agreed only to intravenous hydration and clearly stated he “wanted to go home.” When a chest x-ray revealed a left lower lobe infiltrate, he was admitted for treatment. Upon admission, Palliative Care was consulted. GW’s primary care physician and the Palliative Care Nurse Practitioner met with GW in the emergency room. A lengthy conversation with GW and his mother ensued about what his current condition was, what his clinical options were, what his wishes were at that time and going forward. Using the computerized eye gaze device for communication, he remained able to communicate throughout the meeting. GW received a short course of intravenous fluids and was discharged to home.

Unfortunately, GW was home just a few hours before becoming increasingly short of breath and unresponsive. GW’s mother called 911 and he was transported to a local hospital. GW was intubated and later transferred to the VA medical center.

Providers from HBPC, Palliative Care, ER, and MICU expressed their concerns and offered expertise regarding GW’s worsening respiratory function and impaired swallowing. It was explained that mechanical ventilation and a feeding tube would be necessary if GW wanted to prolong his life. GW directed the medical team to proceed with mechanical ventilation and a feeding tube.

The HBPC and Palliative NP’s continued to meet with GW and his mother, along with MICU staff, to ensure that care was coordinated among multiple disciplines and providers. GW was kept informed of the plans and the obstacles. He and his mother were given emotional and supportive counseling when there were complications or delays. GW was discharged to home on ventilator support and enteral feedings and continues to report satisfactory quality of life.

Discussion: Using ethical principles and virtues to maintain individual and institutional integrity promotes patient well-being. Autonomy is the personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice. Autonomous individuals act intentionally, with understanding, and without controlling influences. Respect for autonomy includes respecting an individual’s right to self-determination, as well as creating the conditions necessary for autonomous choice. GW’s autonomy was implicitly respected. GW was given permission to make the decisions that were consistent with his values at every stage of this process.

Veracity is the obligation to speak and act truthfully and includes the duty to disclose. Veracity demands skillful and patient communication particularly in the early stages of the patient and provider relationship. When multiple providers are involved, the consistency of the message is important.

Lastly, the principle of justice requires equitable distribution of medical goods and services. In the case of ALS, the Veterans Affairs, in 2003, determined ALS is a fully compensable disability. Therefore, GW has a 100% service connection for ALS and has access to all necessary treatments and supports to maintain his quality of life at home.

References:

1. Mitsumoto, H and Rabkin, J. (2007). Palliative Care for Patients with Amyotrophic Lateral Sclerosis “Prepare for the Worst and Hope for the Best”. *JAMA* 298:2, 207-216.
2. Tauber, Alfred I. (2005) Patient Autonomy and the Ethics of Responsibility.

For palliative care consultations please contact the *Palliative Care Program at PUH/MUH, 647-7243, beeper 8511, Shadyside Dept. of Medical Ethics and Palliative Care, beeper 412-647-7243 pager # 8513 or call 412-623-3008, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644-1724, Interventional Pain 784-4000, Magee Women’s Hospital, beeper 412-647-7243 pager #: 8510, VA Palliative Care Program, 688-6178, beeper 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore, and Children’s page 958-3844. With comments about “Case of the Month” call David Barnard at 647-5701.*