

Story from the Font Lines

A woman in her 60s with decompensated cirrhosis was transferred from a neighboring state to Colorado for refractory hepatic encephalopathy. She was not able to make medical decisions due to severe encephalopathy but had previously established her daughter as her medical power of attorney. On admission, she was designated as full code by the daughter, who wanted to continue aggressive treatment. A nasogastric tube (NGT) was placed early in the hospital course due to the patient's aspiration risk. Despite maximal therapy, the encephalopathy continued to worsen. The daughter was unable to visit and expressed discomfort with revising the code status without being able to see her mother's condition in person. As a result, life-prolonging therapy was continued. Several weeks into her hospitalization, the patient developed dark brown NGT output concerning for bleeding and also had an aspiration event that led to increasing oxygen requirement. The patient was transferred to the intensive care unit (ICU) for stabilization and returned to the floor one day later when her respiratory status returned to baseline. Upper endoscopy was performed and showed significant esophagitis from prolonged NGT placement as the likely source of bleeding. The NGT was removed to allow the esophagitis to heal, but the patient was still too encephalopathic to receive anything by mouth. The daughter was contacted again to address the concern of how to deliver nutrition and to readdress goals of care. The primary team reiterated her poor prognosis and the risk for further complications if the present course was continued. The daughter agreed to shift the focus from life-prolonging care to comfort based care. Medical transport was arranged and the patient safely made it back home where she was able to see her family before she died about a week later.

Teachable Moment

This patient received weeks' worth of aggressive, life-prolonging medical care due to a "silent misdiagnosis" of the patient's and family's care goals. Although the medical team did have multiple conversations with the patient's daughter, maximal therapy continued to be presented as the default option despite her daughter's repeated expressions of fear of not being able to see her mother before she passed. When doctors present recommendations to patients, it is important not just to base them on medical diagnosis but also an inference of what the patient's goals and preferences are [1]. Looking back, it is likely that the daughter was trying to communicate the importance of her mother being with family in her final days, but the daughter did not feel comfortable refusing the option of continued aggressive medical care that was presented to her. Surrogate decision maker distress is common, with many expressing guilt about the decisions they made and uncertainty if they did the right thing [2]. Part of this can be alleviated by clear communication from the medical team about a realistic prognosis and strong recommendations when the physician believes they understand the patient's preferences [1].

Silent misdiagnosis of patient preferences and delays in determining goals of care cause harm in multiple ways. Some are direct medical harm from the aggressive interventions often performed at the end of life, such as the esophagitis from the NGT in this case. Others include surrogate distress and increased expenses, both of which are also evident in this case. Improved attention to accurately determining goals of care and communication practices when having these conversations can improve multiple aspects of the patient and family experience at the end of life.

Sources:

1. Mulley, Albert G., et al. Stop the silent misdiagnosis: patients' preferences matter. *BMJ* 2012;345:e6572.
2. Bernacki, Rachelle E. and Susan D. Block. Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Intern Med.* 2014;174(12):1994-2003.