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A Patient/Family-Centered Palliative Care Approach to Decision-making in the Medical Intensive Care Unit

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The intensive care unit (ICU) will remain an important setting for end-of-life care because of the severity of illness of patients in the ICU and because many patients with chronic, life-limiting diseases and their families will opt for a trial of intensive care. ICUs are places where the sickest of patients receive the most technologically sophisticated care that medicine can offer. Because these units care for people at the brink of death, they are also places where patients, families, and health care professionals struggle with decisions about the appropriateness of aggressive care. (Hamric & Blackhall, 2007).

The Event: Mr. O was in reasonably good health when he became "sick" at the mall; 911 was called, and he was admitted to the ED by ambulance with complaints of sudden and severe headache, "sweatiness", nausea, and dizziness. Mr. O was awake, alert, oriented on admission. CT of the head showed subarachnoid hemorrhage that was diffuse and also showed blood in the frontal horns that was concerning for obstructive hydrocephaly. Mr. O quickly gave consent for treatment prior to his family's arrival. He then was paralyzed, sedated, intubated and immediately taken to the neurointensive care unit (NICU) where an extraventricular drain (EVD) was placed to relieve intracranial pressure.

The Family: When the daughter and son-in-law arrived at the hospital, their first images of Mr. O were of being on a ventilator, being motionless and unresponsive, and having part of his head shaved with a device…a drain of some sort coming out of his head. Although they had been given an explanation of the events and of Mr. O's condition over the telephone, they were upset and anxious when they saw him because he had always said that he didn't want to be on a breathing machine.

The family also wondered: How did he get this ill so quickly; what was he going through; would he be okay? Had they missed something they could have noticed? What were they to do? They felt anxious and responsible.

Progress and Setbacks: At first Mr. O. improved. His intracranial pressure dropped to normal, his neuro status improved, and he was extubated. Then, at day 6, he suffered respiratory failure and was re-intubated, developed bacteremia, and developed status epilepticus. The family consented to placement of a ventriculoperitoneal shunt to chronically manage the ensuing hydrocephalus. At 10 days post hospitalization, he was neurologically stable and was therefore transferred to the medical intensive care unit for aggressive management of his respiratory complications.

The Patient/Family Centered Palliative Care Approach to Decision-Making in the Medical Intensive Care Unit (MICU):

Day 1 – Admission to the MICU

Following Robert Wood Johnson Foundation Workgroup guidelines (Mularski, Curtis, et al, 2007), the following were accomplished:

1. Assessment of patient's decisional capacity
2. Documentation of a surrogate decision-maker
3. Documentation of presence and content of the patient's advance directives
4. Documentation of the goals of care.

Mr. O had a written living will and also had designated his daughter as health care Power of Attorney. The daughter and son-in-law were in moral distress because, although they believed that the patient had willingly consented for treatment with the hope of cure, he was now being "kept alive" with "tubes and machines."

The medical team's first priority was to assess the patient for symptom distress. This assessment included: pain assessment and management, respiratory distress assessment and management; and, evaluation of other sources of physical distress (e.g., constipation, increased secretions, etc.). Next, an interdisciplinary team conference with clinicians and family, including a palliative care nurse consultant, was called to develop a plan of care.

National recommendations suggest that a family meeting should occur within the first 72 hours, but because this patient's medical-surgical course of care was known, the team was able to meet with the family again the next day.

Day 2 in the MICU

The interdisciplinary team meeting occurred with the patient's daughter and son-in-law; the attending physician from the MICU and the Fellow; the team social worker and the case manager; and the patient's primary nurse and the palliative care nurse consultant. The patient had not regained consciousness since the insertion of the ventriculoperitoneal shunt. He was requiring full ventilator support and was

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currently being tube fed. He was on day six of antibiotics for a drug-resistant pneumonia (MRSA) and his condition was now complicated by sepsis and ARDS. The daughter and son-in-law were able to express their confusion over Mr. O's expressed wishes and then his subsequent consents for "things he didn't want." Because of the inconsistencies they were unsure about how to proceed with decision-making. The family was reassured that they had done all they could to support Mr. O. They were allowed to express their emotions and grief at what they believed to be his sudden and tragic illness. The family explained that they understood his grave prognosis but they also wanted to give him a little more time to see if he could recover from the infections with the current regimen of antibiotics.

The Ensuing 2 Days

Because of the family's ability to express themselves and their hopes and fears and because they had their questions answered regarding Mr. O's prognosis, they were able to move forward with the following results:

1. Insertion of a tracheotomy was averted.
2. The patient did not receive a "peg" tube for continuation of nutritional support.
3. Family visitation was liberalized.
4. Pastoral care was provided.
5. Music therapy provided music to comfort both the patient and the family.
6. The palliative care nurse consultant began to prepare the family for the steps that would be taken if and when the decision to withdraw care was needed, as Mr. O was showing no signs of improvement.
7. The palliative care nurse also began to prepare the nursing staff for likelihood of ventilator withdrawal.
8. Specific family concerns regarding finances and disposition of the body were identified and addressed by the team social worker who also provided considerable support to the family during this time.
9. The attending medical team ensured that the whole family was apprised of the patient's condition.
10. During this period the daughter was able to make phone calls to other relatives and friends who were then able to come in and say their goodbyes.
11. All care planning was documented in the Interdisciplinary Plan of Care to provide information and insure consistency among all care providers.

Outcome Day 4 in the MICU

Mr. O's daughter, family and friends actively worked through their emotions regarding the suddenness of changes in Mr. O's health status and their moral distress regarding his seemingly conflicting decisions regarding advanced life supports. They were able to feel more certain about the rightness of their decisions regarding withdrawal of ventilator support. The two-day window allowed them to "get ready," and it also allowed staff to provide for emotional and spiritual support. On day four of the MICU experience, the ventilator was withdrawn using a "Comfort Measures Protocol." The patient survived extubation and, with adequate symptom management, was allowed to die a natural death, which took place 14 hours later. The family members and friends were extremely grateful because their psychological and social needs were addressed.

Summary: Quality measures for palliative care in the critically ill and clinical practice guidelines for support of the family in the patient-centered intensive care provide a powerful framework for improvement of palliative/end of life care. Use of these guidelines is attainable and, with the support of the palliative care team, can facilitate decision-making, increase patient/ family comfort, avert costly procedures, and lead to greater family satisfaction.

References

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