INSTITUTE TO ENHANCE PALLIATIVE CARE

# PALLIATIVE CARE CASE OF THE MONTH

## Establishing medical decision-making capacity

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**Case**: Mrs. C was admitted to the ICU (intensive care unit) with gram negative sepsis and profound anemia 4.5 gm/dl and found to have a large hemorrhagic mass, which was found to be adenocarcinoma of the cecum. She was hypotensive and had respiratory distress requiring intubation. Her total bilirubin was climbing, and her oncologist wanted her to have a CT scan of her abdomen to rule out liver metastasis. She had oliguric renal failure, and the patient would require dialysis after the contrast dye exposure. Her past medical history was extensive including peripheral vascular disease, bilateral toe and metatarsal gangrene, diabetes mellitus type II, and she was status post right hemicolectomy with ileostomy placement.

The patient is married, but her husband is also very ill and unable to participate in her surrogate decision making. She has two daughters who live locally and a son who lived out of state, but is at her bedside.

The nephrologist who was called to participate in her care discussed hemodialysis with the patient. The patient was sedated on the vent, but able to shake her head up and down (yes) and side to side (no). When dialysis was discussed, the patient shook her head side to side adamantly. The nephrologists observed that the patient's level of consciousness waxed and waned, but they nevertheless concluded that at the time of their questions about dialysis the patient had capacity to make her own decisions. Dialysis was not initiated.

Palliative care was then consulted to evaluate the patient to determine if she had the capacity to make decisions. After a careful and systematic evaluation palliative care judged that the patient did not appear to have the ability to make her own decisions. She was shaking her head side to side and up and down and appeared to be agitated. The team met with the patient's three children. They did not agree among themselves about the decision to limit any of their mother's care. The son believed his mother would not have wanted dialysis, while the two daughters struggled with any limitations. The patient remained on the ventilator and required further sedation for agitation. She became increasingly hypotensive and vasopressors were started.

**Discussion:** When evaluating a patient's decision making capacity the evaluation should be task specific. Some decisions are more complex than others and require correspondingly greater capacity. For example, a patient with delirium may have sufficient capacity for us to accept their choice to refuse occupational therapy, but not enough to participate in decisions about placement to a nursing home.

Decision-making capacity is assessed according to several criteria. The patient needs to be able to recognize that a decision is required. They must be able to understand the information that is relevant to their decision. They must understand the consequences of each decision. And they must be able to rationally manipulate the information to come up with a decision that is consistent with their value system as far as we have been able to know it. The patient's decision making should be consistent over time. Capacity may wax and wane with sedation and level of consciousness. The patient would not possess capacity if each time a question is asked a different answer is provided.

**Conclusion:** Although the children were not in complete agreement about limiting their mother's care, ultimately they were all able to acknowledge that she would not want to have dialysis. Their mother had a friend who had been dialysis dependant, and she had often stated that she would not want to live that way. Even though the patient was sedated and they agreed that she was not able to make decisions for herself, they validated that this decision was consistent with her value system. During the family meeting, we were asked to come to the patient's bedside because her blood pressure was continuing to decline despite maximum vasopressor support. She died peacefully within minutes despite mechanical ventilation. Her children were able to grieve openly and related that they knew that avoiding dialysis at the end had been the right decision.

**References:**

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