PALLIATIVE CARE CASE OF THE MONTH

"Deciding Who Can Decide: Assessing Decision-Making Capacity in Hospitalized Patients"

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Case: Mr. M is a 70-year-old man with a history of diabetes, CAD, atrial fibrillation, and a history of head and neck cancer who was admitted one month ago with a hemorrhagic stroke. His hospital course has been complicated by respiratory failure and pneumonia. A tracheostomy was placed, though he is currently not requiring mechanical ventilation. Mr. M had a percutaneous endoscopic gastrostomy (PEG) tube previously when undergoing cancer treatment; after he completed treatment, this was removed, and he had been eating by mouth prior to admission. Since his stroke, speech evaluations have found increased risk of aspiration. Currently, he is being fed via a nasogastric tube. He is unable to care for himself at home, and the nursing facility to which he and his family would like him to go is unable to accept him being fed by this route. However, the patient is refusing a PEG tube, indicating that he wants to be allowed to eat regardless of the risks. The nurse at the bedside agrees and says, "He can make his own decisions, we should just allow him to eat!"

Palliative care is asked to see him for goals of care and, particularly, to determine whether it is appropriate to allow the patient to refuse a PEG tube and accept the significant risk of aspiration from eating by mouth, which may lead to his death. The patient is able to communicate by nodding, shaking his head, and mouthing a few words. His arms are weak, and he is unable to write. How should we assess whether Mr. M has the capacity to make this decision?

Discussion: Patients have the fundamental right to make their own decision to accept or refuse treatments, including artificial nutrition. However, in order to exercise autonomy, individuals must have decision-making capacity (DMC). Decision-making capacity is defined as the ability to make a particular decision at a particular time[1]. The level of cognitive functioning required to make a medical decision varies based on both the complexity and the consequences of the decision. For example, naming a surrogate is a generally simple decision that does not require much reasoning or understanding of possible implications. Someone with an impairment may be able to name their surrogate but be unable to manipulate information sufficiently to make a decision about major surgery, which involves a more advanced understanding of the options and has life and death consequences. DMC is not a static quality, and in fact often fluctuates from day to day, particularly in hospitalized patients who may be suffering from conditions such as delirium that wax and wane. Therefore, an assessment that a patient does not have capacity to make a particular decision on one day may need to be repeated on a different occasion when the patient's condition has improved.

[1]Decision-making capacity is sometimes distinguished from *competence* which is often generally considered to be a legal rather than clinical term.

We should have a high level of suspicion for impaired DMC in hospitalized patients, who, in addition to having chronic illnesses that affect cognition and ability to communicate, may be suffering from acute impairments due to their medical condition. Between 20 – 50% of hospitalized patients have impaired decision-making ability (Fassassi et al. 2009; Lepping et al. 2015; Murphy et al. 2018). In another study, when inpatients who were being considered for PEG tube placement were evaluated, 74% lacked DMC (Rahman et al. 2012). When we base our judgment of a patient's decision-making capacity on a general impression, such as observing that the patient appears alert or can nod his or her head "yes" or "no" to a few questions, we are often incorrect (Etchells et al. 1997; Marson et al. 1997). Clinicians who care for patients in the hospital, then, must be able to assess a patient's capacity to make both major and minor medical decisions.

DMC requires four elements: understanding, appreciation, reasoning, and the ability to express a choice. First, a patient who has received an explanation of their condition and treatment options must be able to show that they have a basic understanding of their condition and which treatments are being offered, as well as the alternatives. Common barriers which should be assessed for and accommodated for include low health literacy, low educational level, and hearing loss. A patient with severe cognitive disability, or a patient with delirium or dementia, may not be able to understand the relevant information despite accommodations. The patient must also be able to appreciate the situation and its consequences and apply the medical facts and consequences to themselves. The patient with cancer who, for example, has a persistent delusion that her abdominal swelling is due to pregnancy rather than malignant ascites lacks this element of capacity. The patient must also be able to explain their reasoning of why they have accepted or rejected the offered option. Finally, the patient must be able to express a choice about whether they will accept the procedure or treatment. (Appelbaum 2007)

Patients can express a choice by saying "yes" or "no". An assessment of the other elements of capacity require answers that are more substantial. Some open-ended questions which can help to assess capacity include:

1. What have the doctors told you about your medical problems? Why are you in the hospital? (understanding)
2. What have the doctors said will happen if you do (or do not) accept the treatment? And what are the risks of the treatment? (understanding)
3. What do you believe is going on with your health? Tell me what makes you believe that. (appreciation)

Discussion Continued

4. What do you believe will happen if you do (or do not) accept the treatment? (appreciation)
5. How did you decide whether to accept or reject the treatment? How does that fit in with your goals? (reasoning)

In the case of an individual, such as Mr. M, with deficits due to an acquired brain injury as well as impaired communication ability due to having a tracheostomy, this process may take more time. Suggestions for clinicians interacting with individuals with impairments include the use of a general opening phrase, such as "I have to ask you an important question", to allow for time for auditory processing, to use simpler syntactical structures, including active rather than passive voice and shorter sentences, and simpler vocabulary. Questions may need to be repeated several times in different ways to ensure consistency of responses. Patients with limited verbal or written ability to communicate may benefit from the use of a communication board. Assistance from a speech language pathologist may be useful to determine the best strategies. (Zuscak et al. 2016) Psychiatry consultation is not required to assess capacity, but it may be helpful in the case of mental illness or subtle cognitive impairment. Collateral information from family members may be helpful in understanding whether the values and preferences that the patient is expressing are consistent with the patient's previously stated goals, values, and preferences.

Return to the case: The clinician communicated with Mr. M verbally, using simple, open-ended questions and repeating them several ways. Mr. M communicated back by shaking or nodding his head, making facial expressions, and mouthing words. Some words were audible over his tracheostomy. Mr. M was attentive and engaged, and he was able to say where he was. However, on open-ended questioning, he was not able to state why he was in the hospital or describe his medical conditions. When asked whether he was willing to have a PEG tube, he shook his head "no". When the clinician asked him if he had heard what would happen if he does not have the PEG, he answered, "I don't know". The clinician explained the decision to him, including the risks of eating by mouth versus using a permanent enteral feeding tube. The patient stated that eating was important to him, but he did not repeat back to show that he understood the potential complications of eating by mouth, nor did he show the ability to weigh the benefits and risks of eating.

In this assessment, the patient showed the ability to express a choice but not the abilities to understand his condition, to appreciate the effect of his choices, or to explain the reason behind his decision. The palliative care clinician felt that the patient did not presently have the capacity to make the decision to refuse a PEG tube and take the risk of eating. The clinician recommended that the treating team continue to explain his medical condition and the options to the patient and re-assess his ability to participate in this decision on a regular basis. The clinician also recommended that the treating team reach out to the surrogate to enlist support in making decisions about artificial nutrition.

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