DECISION MAKING CAPACITY
CASE DISCUSSION GUIDE

Discussion – Case 1

Question:
Based on the information you have so far, does it appear that Mr. S has decision-making capacity to leave the hospital AMA?

Answer:
Based on the information available in the short introduction, it does not currently appear that Mr S meets criteria for having decision-making capacity. While he can *communicate a choice*, and the *choice is based on a rational thought process* ("I'm better, and there's a lot to do at home"), it is not clear that he *understands the relevant medical information* and *appreciates the circumstances potential consequences* of his choice.

However, based on the information provided, it is not clear whether Mr S doesn't understand the medical information and consequences because he is incapable of doing so, or because it simply hasn't been explained to him sufficiently in terms he can understand.

Important nuances:
Anytime a patient appears not to meet criteria for DMC based on lack of appreciation of consequences or lack of understanding of the relevant medical information, the first step should be to try to explain the situation and recommendations again, to see if understanding can be gained – among other possibilities, it may be that no one ever explained this to the patient to begin with, or it was done so quickly that the patient couldn't follow the information.

Question:
What additional information would you like? What would be your next step?

Answer:
In this particular example, an appropriate next step would be to explain the medical context and risks/benefits of decisions to the patient again, in terms that you are confident he can understand, e.g. "Antibiotics are a kind of medication that needs to be taken for some time even after you feel better. If you stop right away when you feel better, there is a higher likelihood that you will only feel better for a few days, but then you will get worse again. If this happens, it may be harder to treat you after you get sick again. . . ." Explanations need not be at the level of detail of a physician's (or medical student's) understanding of a topic, but should be appropriate to convey the basic principles of the medical concern, treatment, and risks.

After this step, you can ask the patient to explain back to you when s/he now understands about the medical context and potential risks/benefits of a particular decision. Then, re-

evaluate if DMC exists. In Case 1, the patient may now say "Oh, I understand. I have germs in my skin, and even though I feel better, it could still get worse if I don't take a few more days of medication." Then, the patient may agree to stay, because he feels that this risk outweighs the benefit of getting home sooner. Or, he may decide that he is willing to accept the risk of getting worse, because it is so important to get home to attend to his duties. In the latter case, he may still have decision-making capacity, even if it's not a decision that we might agree with as care providers.

Important Nuances:
As an additional point, this patient does have mild intellectual disability. (Given recent changes in terminology, it may be necessary to educate trainees that this is equivalent to "mild mental retardation" in old terminology.) It is important not to assume that a patient with a mild cognitive impairment or minimal formal education does not have decision-making capacity. Medical explanations and recommendations may need to be tailored for a patient's individual background, but, as in this case, the patient still may have the ability to understand, communicate, and retain decision-making capacity. Along similar lines, a patient who is not a fluent English speaker should have a trained medical interpreter present during any explanations of condition/treatment as well as any capacity evaluations, as difficulties with understanding the language of the provider may be easily misinterpreted as lack of understanding about condition or treatment.

<u>Discussion – Case 2</u>

Question:
Based on the information that you have, does it appear that Mrs R has decision-making capacity to refuse the catheter?

Answer*:*
Based on the information given in Case 2, Mrs. R is clearly able to *communicate a choice* (she does NOT want a catheter). Further, we can imagine that, based on her occupational background, she would typically be able to understand the medical context (the concern for altered mental status and fever, and the need to work it up) as well as the potential consequences of refusing work-up. However, based on her behavior and comments, she appears to be likely delirious, and her usual abilities to *understand the medical context* and *possible consequences* are not present. Also, at this current time, her decision to refuse the catheter *does not appear to be founded in a rational thought process*. Therefore, she does not currently appear to have decision-making capacity.

Important Nuances:
Similar to Case 1 (the patient with mild MR), we must be careful not to let the patient's general background and expected fund of knowledge distract us from the question of whether s/he has decision-making capacity *in the moment*. Decision-making capacity can be fluid and must be assessed at the time of the decision.

Question:
What would your next steps or questions be?

Answer:
Although in this case the absence of decision-making capacity is fairly straightforward, the question of what to do next is less clear. There is no single answer in this case, but the question about appropriate next steps should prompt further discussion and debate among students. When DMC is clearly not intact, this should trigger an addition set of questions to consider; issues that students should consider and discuss include:

1) **Does this constitute a medical emergency, in which consent is implied**? In true medical emergencies, physicians may proceed with treatment even in the absence of clearly communicated consent, clearly intact DMC, or availability of a substitute decision-maker. In cases like this, it is presumed that a rational person with intact cognition would consent to care. An example of such a scenario is that of a victim of a motor vehicle accident who arrives in the ED with life-threatening injuries and altered level of consciousness; in this case, physicians would obviously proceed with care even if DMC is absent.
2) **Can DMC be restored?** In other words, could the condition that renders DMC absent be ameliorated such that DMC would be present? As an example, if uncontrolled pain is preventing a patient from thinking clearly and being able to make a decision rationally, treatment of pain may resolve the patient's incapacity.
3) **Is the intervention really necessary?** Does the severity of the situation necessitate proceeding against her will, or should her wishes be respected even if she does not have decision-making capacity? How necessary is the intervention?
4) **Is there a substitute decision-maker?** Typically, if a patient does not have DMC, the decision would then be made by a substitute decision maker, who may be an individual identified in an advanced directive. If there is no advanced directive, the substitute decision-maker is usually a family member; however, identification of this individual and the hierarchy employed (e.g. spouse, parents, adult children, etc) may vary between states.

Important Nuances:
When the proposed intervention itself is invasive, may cause significant distress, or carries some risk, it should prompt additional reflection on the part of the care team regarding the necessity of the intervention. In this case, if the team felt that obtaining a urine specimen was truly essential for medical care and either the severity of the situation qualified as a medical emergency or the appropriate substitute decision-maker provided consent, steps still could be taken to minimize the patient's distress (*e.g.* medication to manage anxiety or agitation, asking a trusted friend of the patient to be present, etc) prior to the intervention, even if decision-making capacity is not present.

Discussion – Case 3

Question:
Does Mr. B appear to have the decision-making capacity necessary to make this decision?

Answer:
Based on the information presented in the brief vignette, it does appear that Mr. B has decision-making capacity. From what we can gather based on his history, it appears that he is *able to understand the relevant medical information* – he appears to understand the diagnosis and understand what the treatments would be based on his past experience. From his statement, it appears that he has an awareness of the gravity of *his situation and the consequences* of declining treatment. He describes *arriving at the decision by a rational thought process* – i.e. considering the anticipated effects of treatment versus non-treatment, his own goals, and effect on his family. Finally, he is *able to clearly communicate his decision* to his care team without difficulty.

Question:
What would you do next?

Answer:
Although it does appear at initial evaluation that decision-making capacity is intact, next steps would include going into additional detail with the patient regarding each of the necessary components of decision-making capacity. This is especially important given the gravity of his situation and potential consequences of his choices. Examples of additional details to discuss include

- Ability to understand the relevant medical information: Ask in more detail – does the patient understand what metastatic cancer means? Does he understand the difference in diagnosis and prognosis relative to non-metastatic disease? Does he understand what the recommended treatments and anticipated outcomes are, including whether there are differences from treatments that might have be used for newly discovered, non-metastatic cancer?
- Ability to appreciate one's situation and potential consequences of choices: Again, it would be important to discuss in more detail – does the patient appreciate the consequences of his decision *in his particular circumstances* in detail? Does he understand any differences in recommended treatment, associated side effects, and prognosis relative to his prior treatment? Does the patient understand the likely symptoms he will experience if untreated (or treated with palliative care only)? Does he appreciate the difference in his anticipated life expectancy if treated? In a case like this, even though the patient does carry a significant amount of knowledge based on past experience, it is important to make sure that he appreciates how his particular current situation and consequences of his decision may be different from when he was first diagnosed years ago.

- Ability to arrive at a decision by rational means: Can the patient tell you more about how he arrived at his decision? How did he weigh the relative benefits and drawbacks of each option? Are the values he based his decision on consistent with his usual values, beliefs, and personality, or does this appear to be a spur-of-the-moment decision? (Family can also provide useful collateral information about whether the patient's decision-making appears consistent with his usual values, as can advance directives.)
- Ability to communicate a decision: This was intact in the initial vignette, and would need to remain present in further discussion with the patient in order for overall decision-making capacity to be deemed intact regarding this decision.

Another key point brought up by this case is that decisions themselves may change as the patient's medical situation or other factors evolve. In this case, it is possible that the patient's decision could change (and he may wish to pursue treatment) after he has had a few more days to reflect on his situation or discuss further with loved ones. So, while his decision should be respected if DMC is intact, providers should also be aware that ongoing discussion is warranted, and that additional changes may develop as the case progresses. Of note, a change in decision after additional careful thought should be respected. In contrast, rapidly changing decisions, or repeated changes in expressed preferences, should raise concern that DMC may not be present, e.g. because of cognitive impairment that limits ability to reason and remain consistent about decisions.

Important nuances:

In this particular case, the stakes are high – making one decision versus the other may result in a significant difference in life expectancy. In a life-or-death situation or similar high-stakes decision-making scenario, the standards for demonstration of intact DMC must be very high. This is sometimes referred to as a "sliding scale" approach to determining a patient's DMC. That is, a patient's ability to consent to or refuse a fairly benign procedure or medication (e.g. a low-risk pain medication) generally requires a less detailed or sophisticated demonstration of understanding of risks/benefits, etc. In contrast, a high-risk or high-stakes decision necessitates a more rigorous demonstration of decision-making capacity, since the consequences of the patient's decision may be profound. In this case, an evaluator would want to make sure that the patient had a detailed understanding of the prognosis and recommended treatments, and refusal of these treatments. In particular, it would be important to make sure the patient understood that treatment refusal could also bring discomfort and stress to the family (the features of treatment he describes wanting to avoid), and he should have a detailed understanding of what "the natural course" of illness would be expected to look like, including anticipated symptoms, trajectory, and prognosis.

In addition, this case illustrates the difficult fact that patients' disagreement with treatment recommendations can at times be very challenging for providers to understand and reconcile with their own values or opinions. This can at times elicit strong feelings, including frustration, anger, and sadness, on the part of providers. However, if decision-making capacity is intact, the patient's decision should be respected, even if it is contrary to medical recommendations.