

# Assessing Capacity in Psychiatric Patients With Acute Medical Illness Who Refuse Care

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## ABSTRACT

Three cases are presented that demonstrate the difficulty of assessing medical decision-making capacity in patients with psychiatric illness who are refusing care. Health professionals often assess capacity differently in practice. Provided their patients have some understanding of their illness and have some plans for meeting basic needs, psychiatrists are often inclined to give patients the freedom to refuse care even if they do not exhibit a full understanding of the medical facts of their case and why they are refusing it. Adult medicine physicians, in contrast, are inclined to require patients to state a more complete understanding of the benefits and burdens of evaluation and treatment before allowing them to refuse care when their refusals might result in adverse medical outcomes. The 3 cases exemplify the tension between these approaches and highlight the role of hospital ethics consultation in addressing this conflict.

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Health professionals often assess capacity differently in practice. Psychiatrists are often inclined to give patients the freedom to refuse care even if they do not exhibit a full understanding of the medical facts of their case and why they are refusing treatment, provided that these patients have some understanding of their illness and plans for meeting basic needs. Adult medicine physicians, in contrast, are inclined to require patients to state a more complete understanding of the benefits and burdens of evaluation and treatment before allowing them to refuse care when their refusals might result in adverse medical outcomes. We present 3 cases that demonstrate the difficulty of assessing medical decision-making capacity in patients with psychiatric illness who are refusing care, highlighting the role of hospital ethics consultation in addressing the conflict between adult medicine and psychiatry approaches.

## CASE 1

Ms A is a 42-year-old homeless woman who has been in and out of shelters, jail, and the county hospital for several years. Two years ago, she was admitted to the county hospital psychiatric unit after police arrested her for defecating in public and found her irrational and incoherent. Staff knew Ms A well from previous admissions and initiated conservatorship proceedings following a diagnosis of schizoaffective disorder (*DSM-IV* criteria). Ms A has no known living family members; her mother died several years ago.

When Ms A's court date arrived weeks later, her behavior in the unit had improved, and she was stable on medications. The judge ruled that Ms A did not meet standards for incompetency, stating that she did not appear to be a danger to herself or others and that she was able to describe how she would find food, clothing, and shelter. She was subsequently discharged from the hospital.

Since then, Ms A has returned to her previous behavior and has been jailed and hospitalized multiple times for both behavioral and physical health reasons. She has not pursued ambulatory medical or mental health follow-up.

Ms A is hospitalized again, now with pneumonia and a recurrent left lower leg deep venous thrombosis, but is refusing treatment, often turning away saying that she is talking to her mother who is "in a place beyond heaven." The psychiatry consultation note states that Ms A has the right to refuse treatment. Given the acuity of her medical condition and concerned about the consequences of refusal, the hospitalist team requested an ethics consult to evaluate Ms A's treatment refusal and safe discharge.

## CASE 2

Mr B is a 66-year-old man with schizophrenia (*DSM-IV* criteria) who has been living at a psychiatric board and care facility in our community. By all accounts, he has been happy there. A month ago, staff members took Mr B to a local clinic for evaluation of a persistent cough and obvious weight loss. Chest x-ray showed a lesion consistent with lung cancer. He is now hospitalized for a diagnostic workup because attempts at outpatient evaluation have proved too difficult to coordinate.

Mr B agreed to a computed tomography scan at admission to the hospital, which confirmed a diagnosis of lung cancer that appears easily treatable with surgical resection depending on biopsy results. However, Mr B has been dismissing staff, stating, "Let me alone. I just want to die."

- Assessment of decision-making capacity in psychiatric patients with medical illness can be complex and confusing, especially when these patients are refusing care.
- When psychiatrists and adult medicine physicians differ about their assessment of a patient's capacity, formal ethics consultation that integrates both approaches can often provide a pragmatic and empathic solution.

Mr B has a conservator of person, but she states that she does not have the legal authority to make medical decisions for him. Psychiatry consultation affirms his right to refuse care. The hospitalist team acknowledges that Mr B knows that he has schizophrenia, but he refuses to acknowledge his cancer and its proposed workup. Every time the subject is raised, Mr B becomes mute. An ethics consult has been requested to assess whether Mr B can refuse care.

### CASE 3

Mr C is a 54-year-old man who has been living with his 80-year-old mother and 50-year-old sister. Recently, Adult Protective Services was called to their home after garbage began accumulating outside.

Adult Protective Services discovered that the mother was extremely ill and transported her to a community hospital, where she was admitted. The sister was grateful, stating that she was no longer able to care for her mother, who had become acutely worse. She also stated that her brother, who had always been a little difficult, had become abusive, occasionally hitting her.

Police arrested Mr C and took him to the county jail. Over several weeks, deputies noted that Mr C exhibited erratic and bizarre behavior, and they transferred him to the county hospital. The crisis team agreed that Mr C had psychotic features and admitted him to the psychiatric unit with a tentative diagnosis of bipolar disorder (*DSM-IV* criteria). Laboratory screening revealed an elevated calcium level, however, and Mr C was transferred to the medical floor. The endocrinology and psychiatry teams agree that further evaluation is warranted. The endocrinology team does not believe that Mr C's mild hypercalcemia is producing his psychotic behavior independently, but that it is most likely exacerbating an underlying psychiatric illness. The psychiatry team believes that Mr C could be bipolar, but they want his elevated calcium level treated before reevaluating him.

Mr C, however, insists that he is fine. He denies hitting his sister. He acknowledges that "the neighbors never liked me" and states, "I just want to go home," refusing all interventions.

The psychiatry team states that since Mr C is not an immediate risk to himself or others—his sister has dropped charges, and he is able to recite plans for food, shelter, and clothing—his refusal must be honored. The medicine team is concerned that his elevated and increasing calcium level will become an emergency that is preventable with treatment. Mr C, meanwhile, continues to refuse to discuss his medical

condition. His mother remains hospitalized, and although the sister has dropped charges, she does not want to make medical decisions for Mr C. An ethics consult has been requested to discuss Mr C's capacity to refuse care.

### DISCUSSION

The question in these cases is how to assess medical decision-making capacity for patients with psychiatric disorders who also have acute physical illness and are refusing care. Unlike competence, a legal determination established by the courts, medical decision-making capacity is a clinical determination assessed by an individual patient's attending physician.<sup>1-3</sup> Whereas competence is a comprehensive "yes" or "no" determination based on an individual's ability to obtain food, shelter, and clothing and lasting a specified period of time pending reevaluation, capacity is specific and timely and is based on a patient's ability to make a particular medical decision in the moment.

Adult patients are presumed to have medical decision-making capacity unless they are specifically assessed not to have it. Unless there is a particular reason to believe that patients do not have capacity, clinicians usually assess it informally as part of routine care. However, when the stakes of a decision are high, such as when patients are demographically at risk for decision-making difficulties (those at extremes of age, those with illness causing acute delirium, and those with acute or exacerbation of chronic neurologic or psychiatric conditions) or when patients refuse commonly accepted standards of care, clinicians must assess decision-making capacity more carefully.<sup>4,5</sup>

According to Grisso and Appelbaum,<sup>2</sup> medical decision-making comprises 4 distinct subabilities (or steps):

1. The ability to understand information about one's condition generally
2. The ability to appreciate how that information applies to one's own situation specifically
3. The ability to reason with that information, weighing the benefits and burdens of treatment options in order to make a choice
4. The ability to express that choice clearly once made

Spike (J.P.S.),<sup>6</sup> in contrast, believes that assessing a patient's ability to reason with information is too subjective a judgment in a pluralistic society in which patients and clinicians have widely divergent experiences, values, and thought processes. As an alternative, he proposes that what patients demonstrate in step 3, as outlined by Grisso and Appelbaum,<sup>2</sup> is the ability to make a choice consistent with their past medical decisions. In addition, Spike<sup>6</sup> expounds on steps 2 and 4 to include appreciating and expressing comprehension of the *consequences* of one's choice.

Patients have the right of informed refusal, but they must be able to demonstrate the capacity for that decisional choice. That is, they must be able to understand information about their condition generally, they must understand their situation specifically, they must base a decision to refuse

evaluation or treatment on weighing benefits and burdens or on a consistent pattern of past treatment refusals, and they must appreciate what their decision will mean to their future. They cannot “just say no.”

Usually, patients demonstrate these abilities to doctors throughout the clinical encounter, starting with the ability to give a reliable history and then showing enough comprehension of their medical situation to give informed consent or an informed refusal. Capacity, therefore, is not so much an internal psychological condition as an ability to participate in the informed consent process. Often, the moment of certainty for the clinician with regard to capacity occurs when the patient asks a question showing realistic personal concern. The Mini Mental State Examination and related tests are good screening tools for dementia and delirium, but they are not good tests of authentic choice: a patient might be diagnosed with mild-to-moderate dementia yet still be capable of making some medical decisions. These tests are particularly unhelpful in assessing capacity for patients with psychiatric disorders who do not also have a neurologic condition.<sup>7</sup>

Patients who refuse treatment, stating that they have nothing wrong with them, lack the capacity to make an informed decision at that moment. The best approach is to continue to give these patients information, preferably in both verbal and written form, so that they can reconsider their situation and research their condition or discuss their situation with people they know and trust, such as their primary clinician or spiritual advisor. If they say they understand that they may become worse or even die as a result of treatment refusal but can accept that consequence, physicians must document their statement in the medical record and abide by their wishes. Even then, physicians might schedule follow-up to give patients time to reconsider—provided it isn't perceived as harassment, but instead as a genuine act of caring and compassion.

Patients with psychiatric illness do not automatically lose medical decision-making capacity.<sup>3,8,9</sup> Some do have difficulty understanding their illness and appreciating options for care,<sup>10</sup> but most are very capable of making medical decisions<sup>11,12</sup> and have as much of a right to refuse care as other patients. Like everyone else, however, psychiatric patients must base that refusal on something, on some analysis of benefits and burdens or appreciation of risks and consequences. Patients may not like the way a medication makes them feel; they may not want to be tied down to treatments that limit daily activities. These may be acceptable reasons, but psychiatric illness does not free patients from their responsibility to make thoughtful medical decisions. While their reasons do not have to be yours or ours, they must be part of a deeply held and stable part of their personality—not a temporary reaction to news that they cannot understand or assimilate.

It is the responsibility of the medical profession, in turn, to continue to care for patients who are incapable of making an informed authentic choice. It is not the unilateral right of physicians to prevent patients from making poor decisions, but it is unacceptable to allow them to suffer from poor

choices when they do not understand the consequences of what they are deciding. In a free society, we all have the right to make informed “mistakes.” As long as we know what we are doing, we do not have to agree that particular choices are mistakes. Physicians must not allow patients to make harmful decisions reflexively, however, without thinking.

The conflict in these cases is that different physicians sometimes interpret this thinking with different standards. Because psychiatrists frequently interact with the legal system in competency hearings, because most behavioral illness is chronic and fluctuates over time, and because the physiologic consequences of psychiatric illness are rarely irreversible, beyond acute suicidal or homicidal behavior, psychiatrists are generally reluctant to remove decision-making power from patients.<sup>13,14</sup> While the process of psychiatric consultation often facilitates patients' ability to understand their illness, generally, especially regarding social consequences,<sup>15</sup> asking psychiatrists to specifically evaluate medical illness decision-making capacity is often frustrating, as their frame of reference is the mental health system and the courts.<sup>16</sup>

In contrast, because adult medicine physicians face acute medical problems that do not fluctuate but frequently deteriorate without treatment, they are generally reluctant to allow patients to suffer the ill effects of what they perceive to be harmful, irreversible medical decisions. While adult medicine physicians are taught to beware of paternalism,<sup>17-19</sup> asking them to respect psychiatric patients' self-determination is often frustrating, as their frame of reference is the intensive care unit and the morgue.

Stated another way, because of their training and experience, psychiatrists tend to accentuate autonomy and civil liberty and underestimate the complexity of serious medical decisions, whereas adult medicine physicians tend to emphasize beneficence and harm reduction and underestimate the contribution of ineffective relationships and communication skills to patient refusals.<sup>20</sup>

## CASE ANALYSIS

In the case of Ms A, the questions are (1) Does she understand her medical condition and the consequences of refusing treatment? and (2) Is her condition serious enough to override her expressed choice (no treatment) given the uncertainty of her thinking? Of the 3 cases, hers is the weakest in terms of medical urgency. There is no mention that her vital signs are unstable, that she is hypoxic, or that the deep venous thrombosis poses an emergent risk of pulmonary embolism. Still, reviewing Grisso and Appelbaum's criteria,<sup>2</sup> Ms A does not express understanding of her condition generally or her own situation specifically, and she exhibits no ability to reason with the information provided to her. Using Spike's criteria,<sup>6</sup> she does exhibit some consistency with past behavior in that she always refuses treatment—but, then again, she always returns to the hospital when she is ill.

As ethics consultants, we conclude that Ms A does not appreciate the consequences of refusing treatment.

Therefore, since the risk of treatment for the pneumonia is low, the duration of treatment relatively short, and the potential benefit great, ethics recommends treating it in the hospital. In contrast, treating the deep venous thrombosis with chronic anticoagulation is a much riskier proposition for a patient likely to be noncompliant after discharge; the recommendation is not to treat it for now. Lastly, there are very strong recommendations for placement in a board and care facility and for ambulatory follow-up, including reassessment of her psychiatric condition.

In the case of Mr B, the questions are (1) Should the team perform the biopsy? and (2) If the biopsy is positive, should he have surgery? His cancer appears to be easily treatable now, but it likely will not be in the future. Because Mr B refuses to discuss his medical condition, it is impossible to know what he understands about it. He has stated that he wants to be left alone to die, but why? Despite the cough and weight loss, there is no evidence that he is suffering physically. Similarly, there is no evidence that he is suffering emotionally; indeed, the psychiatry teams says that he is stable. His legal status is unclear; he has a conservator who states that she cannot make medical decisions, and there is no other surrogate. Although Mr B acknowledges his schizophrenia, he demonstrates no understanding of his medical condition and no appreciation of its likely consequences. Since no one in the hospital knows Mr B, there is no past history of decision making with which to compare.

Ethics consultation recommends including the conservator in the decision-making process; despite the ambiguity of her legal authority, perhaps Mr B would talk to her, and, together, they could better understand what is at stake. However, if Mr B is incapable of that level of comprehension, perhaps the conservator can provide information about past decisions that would help the team understand him, such as whether he has had previous surgeries and was capable of appreciating what they accomplished. Ethics recommends proceeding with the biopsy to confirm the diagnosis, but only after telling Mr B what was decided and why. Sometimes, that disclosure will act as a prompt, and his response will help us understand him. After that, if the consensus is that the cancer is curable, and Mr B does not actively protest this recommendation, ethics consultation sees clear benefit and recommends that surgery be performed. If at any time Mr B is able to discuss his medical condition and/or if there is other clear evidence that he has refused surgery or medical care in the past, these recommendations must be reassessed.

The broad question for Mr C is how does the team proceed with evaluation of 2 serious illnesses affecting each other, given his statement that he wants to go home? His psychiatric illness is preventing him from agreeing to evaluation of his endocrine condition, his elevated calcium is likely exacerbating his underlying psychiatric illness, and he demonstrates no understanding of either process. Like Ms A and Mr B, Mr C exhibits no understanding of his diagnoses generally or his situation specifically, and he demonstrates no appreciation of the benefits and burdens of care. There is also no documented history of past medical decision

making. Fortunately, he has a sister who has known him his entire life; even if she declines to act as a surrogate decision maker, hopefully she can provide information about his past treatment choices.

Although Mr C's condition is not emergent—at least not yet—because he expresses no understanding of the consequences of refusing treatment, ethics consultation recommends evaluating and treating the hypercalcemia, talking to his sister again about shared decision making, and asking the psychiatry team to reevaluate him once his calcium has normalized. His simple statement, “I want to go home,” is not enough. As with Mr B, if Mr C finally does participate in discussing his situation, this set of recommendations must be reassessed.

## SUMMARY

In the 3 cases presented, patients are unable to be informed about evaluation and treatment of acute medical illness. Thus, they are not cases of informed refusal but are cases of noninformed refusal in the context of patients with underlying psychiatric disorders that prevent them from having medical decision-making capacity. Some might argue that the use of formal capacity assessment tools such as the Aid to Capacity Assessment<sup>21,22</sup> or the MacArthur Competence Assessment Tool<sup>2,23</sup> would improve certainty about the lack of decision-making capacity and subsequent ethics recommendations. Both of these tools require patients to discuss their medical care; however, they would not be useful in these cases.

When possible, engaging a patient's primary medical care or psychiatric clinician who has a relationship and history with the patient can provide both medical and social context to help resolve these situations. When that is not possible or is insufficient, however, formal ethics consultation, integrating both the psychiatric and hospital medicine approaches to capacity and finding an empathic and pragmatic solution for care, is the best way to help in these cases of refusal of care.<sup>24–26</sup> Different consultants—whether teams or individuals—may make different recommendations, but the comprehensive deliberative process of ethics consultation provides the best opportunity to optimize care in these complex clinical scenarios.<sup>18,19,27</sup>

Although the courts are always involved in legal competency determinations, courts are generally reluctant to address immediate clinical issues of medical decision-making capacity and medical treatment: legal processes often take months, and legal proceedings are adversarial, not therapeutic, by design. Still, in some institutions and in some geographic regions, the practice might be to involve legal counsel, especially if treatment involves surgical intervention. Clinicians must be aware of local norms.

Psychiatric patients with acute medical illness are often challenging and frustrating. They require and deserve our very best, which includes honoring informed treatment refusal, when appropriate. However, treatment should not be withheld for patients who do not understand what they are refusing when the risks of that refusal are high. While



the patients in the cases presented here expressed a choice to “just say no,” our analysis is that their understanding is compromised. Using the ethical discourse of the 4 principles of biomedical ethics,<sup>17</sup> beneficence, nonmaleficence, and justice outweigh uninformed autonomy. Doing good, preventing harm, and providing care to this vulnerable population require careful action and close follow-up.

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