

Refusal of Care: The Physician-Patient Relationship and Decisionmaking Capacity

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Problems of refusal of care, among the most common ethical dilemmas in the emergency department, are also often the most difficult to resolve, pitting 2 conflicting duties, that of helping patients and that of respecting their autonomy, against each other. Using a case presentation as a backdrop, this article offers a practical approach to patients who refuse treatment, including assessment of decisionmaking capacity but emphasizing the role of trust, communication, and compromise in these cases. [Ann Emerg Med. 2007;50:456-461.]

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CASE

An 82-year-old man was brought to the emergency department (ED) by ambulance after vomiting on a bus. He reported 3 days of nausea without vomiting. The patient denied pain, as well as any medical history, surgical history, or medications.

On examination, the patient was a well-developed, well-nourished man in no acute distress. Vital signs were blood pressure 150/90 mm Hg, pulse rate 103 beats/min, respiration 14 breaths/min, and temperature 97.7°F. The only finding on physical examination was a pulsatile midabdominal mass. His neurologic examination, including Mini-Mental Status Examination, was unremarkable; he was cooperative with appropriate affect but appeared wary. Computed tomography revealed an intact, 8 cm, abdominal aortic aneurysm.

The patient, told that the aneurysm would likely be fatal if not repaired, refused surgery, saying he did not like physicians. He acknowledged that he therefore would probably soon die but would not discuss the issue or give family contacts. At this point, the team considered admitting him involuntarily.

DISCUSSION

Problems of refusal of care, among the most common ethical dilemmas in the ED, are also often the most difficult to resolve, pitting our duty to help patients against our duty to respect their autonomy. Often, the approach to such cases consists solely in assessing the patient's decisionmaking capacity. A patient who refuses care either has capacity and should be discharged against medical advice (AMA) or lacks capacity and must be treated against his will. Using this approach, case discussions of patients who refuse recommended treatment often immediately jump to a discussion of capacity. Focusing on this technical question, however, obscures what is usually our

primary obligation in these cases: understanding and, if possible, addressing the patient's underlying reasons for refusing care. In the majority of cases of refusal of care, the problem is a failure not of capacity but of communication.¹ The patient does not understand us, or we do not understand him or her. In these cases, we have failed to meet our ethical responsibilities to our patients if we simply discharge them AMA. We are obligated to do our best (without coercion) to help patients overcome their reluctance to accept care that is in their best interest. Only by talking to them, to find out what their concerns are and to respond to these concerns, can we do this. Even with patients who lack capacity and will not be allowed to refuse care, such communication is important because it may help us devise a plan with which the patient will cooperate, such cooperation being ethically and technically preferable to struggling with a combative patient.

The approach outlined in this article to patients who refuse care, emphasizing that good physician-patient communication is at least as important as the ability to assess capacity, helps avoid the pitfall of the "AMA/no capacity" dichotomy, which is not to say that a consideration of capacity is only necessary when all else fails. If lack of capacity is self-evident, we must immediately look for a surrogate decisionmaker (if circumstances permit). Likewise, before a patient decides on a care plan, we should be comfortable that he or she has the capacity to do this. Thus, in actual practice, communication and capacity assessment occur in parallel. In concept, however, our primary concern must be preventing intractable conflict rather than resolving it through capacity determinations. Therefore, our consideration of the problem of refusal of care will begin with a discussion of methods for preventing, or at least minimizing, these conflicts. Only then will we turn to issues surrounding capacity.

Preventing the Problem: Enhancing the Physician-Patient Relationship

Because, as we mentioned above, most cases of refusal of care are a result of poor communication, the first object of our attention in such cases should be this communication and the relationship that frames it. Thus, when disputes arise, we should examine the physician-patient relationship to see how we can strengthen it. Likewise, forming a good relationship initially is the best way to prevent these disputes.

Developing such a relationship requires effort, particularly in the ED, with its pressures and distractions and the short time available to interact with patients we do not know. Several skills and virtues are involved in developing this relationship or in repairing it if we notice signs of a problem, such as a patient's refusal of care.

The primary skill is clarity in communication. One impediment to forming a therapeutic alliance can be the patient's failure to understand us. Physicians forget how much they learned during training, often using terms incomprehensible to laypeople. We must use language patients understand. A patient who does not understand us is unlikely to accept our recommendations.

A patient who understands us but still declines to follow our advice may not trust us. Placing one's health in the care of a stranger requires deep trust. There are many ways of fostering trust during a brief ED encounter. Responding to a patient's small immediate needs, such as an extra blanket, shows that his or her interests are important. Assuring the patient that you will involve their primary physician allows you to tap into the trust the patient has for that physician. If some distrust has already surfaced, a simple statement that you have the patient's best interests at heart may help. Besides all of these strategies, however, the best tool for establishing trust is attention. A physician, standing between stretchers, distracted by surrounding events, seemingly in a rush to move to the next emergency, may not inspire trust. Such behavior is understandable, even natural, in the ED but must be avoided. Our patients deserve our full attention, which does not mean ignoring the rest of the ED but simply that, at the moment we are with a patient, the patient must sense that our encounter is of primary importance. The ability to convey this focus is an essential skill. Exercising this skill may require patience, an essential virtue here, for we may need to let the patient talk, and think, for longer than we might otherwise want. This extra time will be well rewarded.

Empathy is the second essential virtue for developing trust. A patient who thinks that we not only are listening to him or her but also appreciate his or her distress is more likely to enter into a therapeutic alliance with us.

An encounter imbued with attention, patience, and empathy will not only foster trust but also help the patient talk. Only if patients open up to us can we discover their concerns, especially those that may prevent them from accepting needed care. There are many such issues we may uncover. Brock and Wartman²

mention, among others: failure to adequately consider the long-term consequences of a choice, inordinate fear of pain, and failure to consider low-probability but high-cost outcomes. To these we may add denial, need to maintain control, and fear of being stigmatized. This last may be especially prevalent among patients who expect to be admitted to AIDS floors. Whatever the issues, we cannot help patients deal with them, as by explaining that there is no AIDS floor, unless they talk to us.

Mitigating the Problem: Negotiation

Improved communication may thus help us prevent our problem altogether. However, the effort we put into strengthening our relationship with our patient will aid us even if, despite the effort, the patient refuses care. Often, there is room for negotiation, for which understanding and communication are again essential. We generally recommend to our patients the plan we consider optimum. However, there are often other acceptable possibilities. All reasonable options should be explored. Perhaps a patient who refuses admission for a major evaluation will agree to tests in the ED. If so, order the tests, even if they are normally done for inpatients only. If positive, the results may convince the patient to accept care. If negative, it may be easier to discharge the patient comfortably. The more information available, the easier it is to reach agreement. If a patient continues to refuse, offer to call family, friends, clergy, or a personal physician with whom he or she might be willing to talk and who might prevail on the patient to accept treatment.

Sometimes, when further care in the ED is not an option and the patient must either be admitted or sent home, actual compromises in the care plan may be necessary. Consider a patient who refuses to be admitted for an urgent cardiac catheterization planned to occur in 6 hours because he has not eaten all day and refuses to remain with an empty stomach any longer, as the cardiologists insist. If he persists in this refusal, he should probably be allowed to eat. Certainly, his eating may delay the catheterization, which would be undesirable. However, the patient may be more amenable to consenting to treatment when he is not having acute hunger pangs. Better to defer the catheterization overnight because the patient ate than indefinitely because he left the hospital AMA. Finally, even someone who refuses all interventions, consultations, and variations in the plan may agree to be admitted overnight for observation. He does not have to agree to the whole plan for us to begin carrying it out step by step as he consents to it. Although observation itself may add little to the care of some patients, admitting the patients gives us, or perhaps initially unavailable family and friends, more time to discuss with them their objections and perhaps convince them that treatment is in their best interests. Once a patient has left AMA, however, he or she is unlikely to ever return.

We emphasized above that communication is essential even with patients we believe lack capacity. Anticipating our discussion of capacity, which follows below, one might ask why we should negotiate with a patient we believe lacks capacity.

After all, many of these patients are difficult to talk to, and even if we can talk to them, we will not ultimately let them refuse, so why bother? Certainly, there are patients who so profoundly lack capacity, because of severe dementia, for example, that any conversation is pointless. However, for those patients with whom we can talk, whether we are sure they lack capacity or merely suspect it, discussion and negotiation are still vital. First, it is always ethically preferable not to coerce patients into treatment, whether or not they have the capacity to refuse it. Second, as we mentioned above, whether or not the patient has capacity we will often need his or her assent and cooperation to carry out any treatment plan, which may require compromises even with patients who lack capacity. What would be good for a compliant patient may not be best for one without capacity who will not cooperate with the standard treatment for a condition. If the patient will not take antirejection medications, perhaps the kidney transplant he or she is refusing must be replaced with dialysis, even if that would otherwise be suboptimal.

There are 2 further points to make about these negotiations, both of which apply regardless of the patient's capacity. First, it may appear that in some cases there is no room for compromise. This is true only in a limited set of cases. The occasions when an immediate decision on essential therapy is necessary, ruling out even the option of admission without treatment, are few. In all other cases, some negotiation should be possible. Second, we must avoid manipulation and coercion in these negotiations because that would violate the same autonomy we seek to respect by allowing patients to choose their own course of treatment.

Decisionmaking Capacity

Sometimes, during our discussions with a patient, we may begin to suspect that the reasons for refusal lie not in the communication issues we have been discussing but in the capacity to make appropriate choices. When this happens, in addition to our negotiations, we must assess the patient's decisionmaking capacity. If the patient has capacity, we should abide by his or her choice. However, if the patient lacks capacity, we must turn elsewhere to determine how to treat him or her, even, indeed, if the patient agrees with the proposed care.

Often, there will be little doubt about a patient's capacity, as in the case of the severely demented patient, or, conversely, the well-groomed coherent young man who agrees to an appendectomy. To be able to determine capacity in other cases, we must first understand the concept.

Let us begin by considering why we are required to respect a patient's choices. This requirement is grounded in 2 presumptions. First, we want to maximize a patient's good, and we have concluded that, generally, people are best at knowing what is best for them. Second, we believe there is value in respecting people's autonomy, allowing them to make their own decisions, regardless of the benefit particular decisions bring them.³

Consideration of these presumptions makes it clear that not all patient decisions must be respected. If the patient is *not* able to determine what is best for him or her or if, in choosing, the patient is not acting autonomously, our reasons for respecting the decision are reduced or removed. In that case, our obligation to protect and benefit the patient comes to the fore. The question of decisionmaking capacity, then, is the question of whether a patient's decision expresses the choice of an autonomous person capable of determining what is best for himself or herself.

With this understanding, we can appreciate a practical account of decisionmaking capacity. An oft-cited report of the President's Commission states that decisionmaking capacity comprises 3 attributes: the possession of a set of values and goals, the ability to communicate and to understand information, and the ability to reason and deliberate about one's choice.⁴ How do these criteria capture the presumptions we discussed above? First, to choose what is best for oneself, one must have a sense of what outcome would be best ("a set of values and goals"), "understand information" about the current state of things and the options available, "reason" about how different choices will lead to different outcomes, and (trivially) "communicate" one's choice. If any of the requirements are lacking, one cannot reliably make decisions leading to one's preferred outcome. Autonomy, too, is expressed in these attributes because the essence of autonomy may be said to be the possession of one's own set of values and goals and the ability to act on them as one sees fit. If one lacks these goals or is incapable of correlating one's actions to these goals, one cannot act autonomously.

Assessing Capacity

In practice, we need more than an abstract understanding of these attributes. To determine whether a given patient has decisionmaking capacity, we must be able to assess whether he or she possesses them. Ultimately, we can do this only through attentive conversation with the patient. The following 3-step process can help elicit the required information.

First, give the patient all relevant information: his or her current condition, the therapeutic options (including doing nothing), and the risks and benefits of these options. This information must be understandable (as discussed above), complete, and accurate. Completeness means giving the patient all of the information a person needs to make this decision. Accuracy entails not only giving correct information but also not exaggerating or underplaying facts to influence the patient. Telling a patient she will likely die if she leaves when you know the risk of death is 1 in 50 is essentially lying and violates the patient's right to make free and informed decisions.

Next, have the patient paraphrase what you have just said, which allows you to assess his or her understanding of what you have said, as well as to correct any misimpressions that have arisen. To avoid offending the patient, you can preface this request by explaining that you want to make sure you have been clear.

Finally, after the patient expresses a choice, ask him or her to explain the reason for the choice. This enquiry can shed light on all of the attributes of capacity. Some patients may give an understandable reason for an apparently surprising choice, leading one to accept that they have capacity. On the other hand, a patient who gives an apparently inappropriate reason, such as “I have a hairdresser’s appointment tomorrow,” for refusing admission for necrotizing fasciitis appears to lack at least 1 of the attributes. Either the patient does not understand the grave danger or, if he or she understands this on one level, is unable to take the logical step “If I die tonight, the appointment doesn’t matter.” If we assume the patient understands all this, we may conclude that he or she is not using a set of values and goals because it is difficult to imagine a set of values that places the inconvenience of rescheduling the hairdresser above a high likelihood of dying. Patients who can give no reason for their decision likewise lead us to conclude that they have no reason, raising doubts as to whether their decision is the result of rational informed deliberation rather than an unthinking whim.

Thus far, in determining capacity, we have been focusing on the rationality of the patient’s deliberations and not the choice he or she is making. This focus on the deliberative process rather than the outcome emphasizes that we are evaluating a patient’s ability to engage in a process: autonomous decisionmaking. However, does the particular choice the patient makes have any broader role in our capacity determination? Does it matter whether the patient is agreeing or disagreeing with us or how high the stakes are?

To start by answering most generally, the patient’s decision clearly has *some* role here. We begin all encounters with the presumption that the patient has decisionmaking capacity.⁵ Sometimes this presumption will be overcome by obvious deficiencies in the patient’s mental status. However, other times, the first clue we have that an otherwise lucid patient may lack capacity is his unexpected refusal of what seems to us to be an obvious course of treatment. A patient who appears to be “irrationally” endangering his health or life warrants closer assessment, even if he is ultimately found to have capacity.

Does the particular decision made have any role in our capacity assessment beyond triggering it? Does the process of assessment differ, depending on whether the patient agrees to or refuses the proposed treatment or on the risk the patient is undertaking (even in agreeing with our recommendations)? Wear⁵ claims that the answer to all these questions is no. Wear⁵ argues that although the patient’s decision may be one of the triggers for putting aside the presumption of capacity and engaging in a formal assessment (along with obvious behavioral abnormalities or anxiety, the presence of sedatives, developmental delays, hypoxia, and perhaps extreme old age^{3,5}), once we do initiate the assessment, we ignore these factors and focus on the patient’s ability to carry out the decisionmaking process. The outcome of the process is not relevant, just as the sedatives are not as long as their presence is not affecting the patient’s decision processes. Patients who agree with us are

assessed just like patient who disagree, and the risks involved in the decision do not affect the assessment either. Wear’s⁵ primary motivation for this approach is that the physician, by making a recommendation, determines whether the patient’s choice is an agreement or disagreement, and likewise, it is the physician’s risk assessment that would be used under the alternative. But the physician’s personal beliefs about which course of action is best and how risky various options are, are not strictly related to the patient’s capacity and thus should not be considered in an assessment. The patient’s ability to understand these beliefs *is* relevant, but this can be assessed without attention to the patient’s choice. (Wicclair⁶ adopts a similar position.)

Most commentators do not agree with Wear⁵ and Wicclair,⁶ arguing that the decision made by the patient is directly relevant to the assessment carried out.^{1,3,7-9} Patients considering a risky treatment, even if they agree, and patients who refuse care (who are presumably choosing a more risky option) should be held to a higher standard when their capacity is determined, which is often referred to as the “sliding scale” of capacity. Patients must display a greater degree of capacity to make some decisions than others. In practice, this means requiring greater clarity and understanding from the patient before accepting a high-risk decision because this is the primary way patients demonstrate their capacity. This requirement will often necessitate that we receive more elaborate and specific answers in the assessment outlined above. Thus, whereas a patient consenting to a lumbar puncture to evaluate a suspected subarachnoid hemorrhage could give vague responses about a needle in the back to check for blood in the brain and be considered to have demonstrated capacity, one who wanted to refuse this procedure would have to demonstrate a clear understanding of the procedure (to show that he or she knows how relatively minor it is), as well as a clear understanding of the nature and risks of an undiagnosed subarachnoid hemorrhage (so it is clear that he or she knows why detection is urgent). Similarly, a patient choosing between stenting and an operation on blocked carotid arteries must evince greater understanding of the choices than one deciding whether to have a small laceration sutured or Steri-stripped.

The justification for this double standard is that we must always balance our respect for a patient’s autonomy, which, as we noted above, is expressed through their decisionmaking capacity, against our responsibility to protect the patient from harm. Respect for autonomy in general takes precedence, but the latter obligation is never absent. The more impaired the patient’s autonomy and capacity, the less valuable protecting that autonomy becomes. At the same time, the greater the risk the patients would be taking on by their decision, the more significant the issue of protecting them from harm becomes. In requiring patients making risky decisions to demonstrate greater capacity (and hence autonomy) through greater clarity of understanding and thought, we are seeking to balance our 2 competing obligations. Patients who demonstrate that they have no significant defect in their decisionmaking capacity will be allowed to make even high-risk decisions. As their degree of

impairment increases and their degree of autonomy decreases, they will be allowed to take on less risk. Conversely, patients who are not taking on significant risk with their decision do not need to demonstrate a significant degree of capacity (even if they possess it).³

Even authors who do not think there is a sliding scale for capacity according to the risks involved agree that capacity determinations are case specific. Just as one may have the capacity to program a computer but not to repair one, one may have the capacity to sign a do-not-resuscitate order but not to refuse surgery on an abdominal aortic aneurysm. Different decisions require understanding different facts of potentially differing complexity and emotional resonance, and these differences may affect one's capacity.^{1,10} Similarly, a patient's capacity to make a given decision may vary within a single hospitalization or day. A patient who lacked capacity to refuse a first lumbar puncture while delirious must have his capacity reassessed before we overrule his objections to a follow-up lumbar puncture after the delirium resolves. Similarly, consent to a first lumbar puncture given while a patient has a clear mental status cannot simply be carried over to the next day when increasing somnolence prompts a second look for blood.

Patients Who Lack Capacity

In the event that we conclude that a patient lacks capacity to make his or her own decision (regardless of whether or not he or she is agreeing with us), do we simply carry out the plan we would recommend to the patient if he or she had capacity? We might, but only as a last resort and only sometimes. Our first responsibility (if there is time) is to see whether the patient has left us any guidance in the form of a written advance directive dealing with our case or has a surrogate decisionmaker. A surrogate decisionmaker is someone who is legally authorized to make decisions for a patient when the patient is unable to do so. In some states, such as New York, only a health care proxy, designated in writing, can assume this role. Relatives as such have no official standing.¹¹ Other states create a hierarchy of relatives (spouse, then child . . .) who can assume decisionmaking for the patient when the patient lacks capacity and there is no designated proxy.¹² Of course, even in states such as New York, where the family lacks legal standing, their input is important. Whatever decision we make will affect them, and we may consider this. Furthermore, they may have knowledge of the patient's wishes and values, which may (and, in some states, must) guide our decisions about what to do for the incapacitated patient.

If there is a surrogate or advance directive, then, we must allow the surrogate or directive to guide our care of the patient, regardless of what we think is best for the patient. Only if there is neither of these or no time to find out about them may we and must we act in the patient's best interest as we understand it. Determining a patient's best interest, however, can be

difficult. We saw above in our discussion of negotiation that for a noncompliant patient, the theoretically ideal plan may in fact become an inferior choice. The decision of what is in a patient's best interest must be tailored to the circumstances. We must not completely discount the desires of the patient simply because he or she lacks capacity.

Further Points

Before concluding this discussion of capacity, I must make several other notes about the process outlined earlier. First, although the process requires that the patient communicate with us, this does not mean that a patient who will not talk to us necessarily lacks capacity. He or she may simply be ornery. Lack of communication bespeaks a lack of capacity only if it is the result of inability, not lack of desire. In the latter case, a different set of tools, beyond our scope here, is needed.^{13,14}

Second, the presence of mental illness is neither necessary nor sufficient for determining that a patient lacks capacity. One can lack capacity for other reasons, such as dehydration, and the presence of mental illness, unless it directly affects the patient's relevant thought processes, does not strip the patient of capacity. A schizophrenic patient may have the capacity to make many medical decisions. Only when his or her delusions and hallucinations interfere with the ability to assess the choice at hand has he or she lost capacity. A corollary to this point is that, barring any local hospital policy, it is not necessary to call a psychiatrist to make a capacity determination. Assessment of capacity is best made by the physician caring for the patient.³ Only if the physician is uncertain whether he or she understands the patient's thought process should a psychiatrist, who is by training expert at this understanding, be called.

Two other consultants who may be helpful, but who do not necessarily need to be involved, are ethics and risk management experts. Ethics consultants may be helpful in determining where on the sliding scale our case lies. Also, many hospital ethicists are experienced mediators who may be able to facilitate the communication we have been emphasizing. Finally, if a patient's capacity is in doubt, it may be useful to call risk management. Although it is not their place to determine capacity, risk managers may be familiar with local court decisions that bear on the case. Also, contentious cases may result in litigation, and the hospital will be best prepared if it was aware of the case early.

Case Resolution

Despite interviews with physicians, social workers, and a chaplain, the patient continued to refuse care or even to discuss it, saying only that he did not want it and did not like physicians. With the concurrence of a psychiatry consultant, it was determined that the patient showed no evidence of engaging in informed deliberation of a life-and-death decision

and therefore lacked capacity to refuse surgery. He was admitted involuntarily but died when the aneurysm ruptured before surgery.

CONCLUSION

Disputes between physicians and patients are often resolved by assessing the patient's capacity. However, capacity assessments are blunt instruments, often leaving us with just 2 possible outcomes, both undesirable: treating a patient against his or her will or allowing the patient to be endangered by leaving AMA. Preceding and accompanying our capacity assessments with clear communication and a strong physician-patient relationship will often help us to prevent these conflicts altogether and, when this is not possible, to mitigate the impact of these disagreements on the patient's welfare, whether or not the patient has decisionmaking capacity. The close attention to our interactions with our patients advocated here is thus vital to meeting our ethical responsibilities to our patients.

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