ORIGINAL INVESTIGATION

When Patients Refuse Assessment of Decision-Making Capacity

How Should Clinicians Respond?

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When patients refuse beneficial treatment, the assessment of decision-making capacity plays a key role in determining the best course of action. However, situations in which patients refuse to explain their reasons occur. This can make an assessment of capacity impossible. In such cases, clinicians find themselves in difficult situations without clear ethical guidance. Refusal to give reasons for refusing beneficial treatment has been seen as pointing to the absence of decision-making capacity. However, the reasons given for this are either unsatisfactory or insufficient to eliminate cases of genuine uncertainty. This article argues that although it cannot be concluded that such patients are incompetent, there are reasons to treat them as if they were. The basis of this possibility, however, points to several obligations for clinicians before such a situation can be said to exist. *Arch Intern Med. 2004;164:1757-1760*

It is considered important that ill persons should receive the necessary care to restore their health whenever possible, or at least to better their functioning and alleviate their suffering. It is also considered important that people should be free to make their own choices, if these do not harm others. Therefore, there is a wide ethical consensus that competent patients should be free to accept or refuse medical interventions. Decisions about interventions for incompetent patients, on the other hand, will be made based on their prior stated wishes, the help of a proxy, their objective best interest, or a combination of these. Capacity assessment, the evaluation of the abilities that patients need to be considered competent to make their own health care decisions, thus, has a key role in helping clinicians determine what they should do when patients refuse beneficial treatment.

The most difficult cases are those in which a patient refuses beneficial treatment, and in which decision-making capacity cannot be assessed.

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CASE ILLUSTRATION

The following case should serve to illustrate what these situations can look like, and highlight some of the difficulties involved.

Irene is a 78-year-old retired professional who lives alone. She comes to the clinic because she is having difficulty walking. She states that she has barely been able to get into the taxicab she took to come. This is her first visit. She has had no regular physician since her previous one died. Her left leg has been hurting for a few days. On physical examination, there are clear signs of an extended infection. Her left foot is inflamed and swollen, and she has an enlarged left inguinal node. She has no fever. Her medical history is unremarkable. The plan is to initiate antibiotic treatment, but the fact that the patient can barely walk is concerning. She is usually independent, and will be unable to care for herself for at least a few days. She has no family or close friends, and usually walks every day to buy her food from a nearby store. The results of a blood test show marked hyperglycemia. She was never diagnosed as having diabetes mellitus before and will require close monitoring of her glucose levels and infection. Admis-

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sion to the hospital is advisable to initiate treatment. She accepts this and seems relieved. The next day, however, she becomes fretful and asks to go home. Her serum glucose levels are better, but insulin is still required. The infection has spread a little during the night, and the patient can barely walk a few steps. When this subject is raised, she thanks the staff for their concern but persists in her request and becomes insistent. When asked for her reasons, she refuses to answer. The physician supervising her care is called to talk with her and assess her understanding of her situation. During the interview, the patient is calm, but defensive. She insists that she has no wish to discuss her decision.

Determining the best course of action in such cases can be very frustrating. Several strategies have been proposed to resolve these situations, but each is problematic.

DO THESE PATIENTS LACK DECISION-MAKING CAPACITY?

It can be mistakenly tempting to assume that patients who refuse beneficial treatment lack decision-making capacity. The assessment of decision-making capacity is not based primarily on what the patient chooses, but on how the patient chooses. Refusal of beneficial treatment does indicate the need to assess decision-making capacity to ensure that the choice is autonomous. However, it does not mean that a patient lacks decision-making capacity.

Refusal to give reasons does not point to incompetence either, although this view has been defended.[1] Refusal to give reasons frustrates attempts to assess capacity, but the fact that an ability cannot be assessed does not mean that the patient lacks it.

IS THERE A DUTY OF CONVERSATION?

Clinicians have a duty to do their best to convince a patient to accept a treatment they consider in the patient's best interest.[2,3] Because dialogue fosters better decision making, it has been argued that patients have a similar duty of conversation.[2] But patients may not always accept this view. A patient who will not engage in dialogue can still be making a valid decision.

Clinicians should certainly attempt assessment of decision-making capacity in situations of treatment refusal, because this could help them understand the patient's goals and sometimes lead to the diagnosis of conditions that impair autonomy.[4] They should do their best to evaluate the patient's understanding of the relevant information, the patient's appreciation of the significance of this information for the circumstances, the patient's ability to reason with the relevant information and weigh options logically, and the patient's ability to express a choice.[5] In determining the necessary threshold of understanding and reasoning ability, they should consider the degree of risk to the patient if the patient's wishes are followed.[6] Physicians, then, do have a duty of conversation. However, extending to patients an obligation to discuss their reasons is problematic.[7] An assessment of decision-making capacity can include probing for personal elements, such as fears, doubts, and mental abilities. It is an intervention. For competent patients, interventions are subjected to patient consent. There is no compelling reason for a capacity assessment to be considered differently. Of course, this intervention is the one that is needed to determine whether its own refusal is autonomous. But this difficulty cannot be shied away from by giving this intervention a special status. In addition, enforcing assessment of capacity requires forcing the patient to answer questions. If persuasion does not suffice, forcing the patient to answer questions to determine capacity is not an acceptable option.

REQUESTS TO BE LEFT ALONE

When patients ask their physicians to leave them alone, an additional difficulty appears. Clinicians recognize, and are expected to observe, a duty not to abandon their patients.[8] This, of course, does not mean that they are under an obligation to treat autonomous patients who want to be left alone. If a patient makes a decision that goes against the patient's presumed interest, however, the patient's clinician could be bound by this duty to try to verify that the patient is not making this choice in an irrational manner (eg, the patient is not basing the decision on implausible presumptions about consequences or reasoning in an illogical way).[5] How much a physician can insist on an explanation, however, remains problematic. The clinician-patient relationship is not and should not be of such a nature that only the clinician can decide when it ceases to exist, with the patient a captive of the clinician's duties. Nor could giving an explanation be considered a prerequisite before a patient could leave.

CHOOSING RISKS IN UNCERTAINTY

These situations are extremely challenging for clinicians. Clinicians simply do not know if these patients have the capacity to make decisions regarding their own health care. If clinicians consider that these patients do have decision-making capacity, they risk not responding to the real need of some incompetent patients. However, considering patients to lack decision-making capacity when they will not give their reasons is problematic too. They may be making a perfectly autonomous choice not to discuss their reasons. The fact that assessing decision-making capacity is impossible does not mean that the patient is incompetent.

Cases such as the one described, when they are viewed as placing the patient in danger, sometimes lead to the involvement of judicial authorities. However, this merely removes the nominal responsibility from physicians, because their assessment is likely to remain decisive.

Considering the degree of risk to the patient can also help answer the following question: how certain should clinicians be that a patient who expresses a choice is competent? It does seem that a low degree of certainty would be sufficient in low-risk cases. The difficulty would be to determine a threshold in cases in which the added risk of following the patient's choice is significant. One way of examining this is to ask what would be risked by erring on either side of this issue.

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Risks to Incompetent Patients

If clinicians treat these patients as though they had decision-making capacity, it will lessen the protection of some incompetent patients. If the risk to them is high, this would be a point against taking this stance. In addition, lessening the protection of incompetent patients is not only a risk to the individual patient in a given case. The social goals of medicine have been described in terms of public health, and have included such nonmedical goals as assisting criminal justice, for example, or the ascription of rights, responsibilities, and opportunities based on health status.[9] However, another social function that medicine plays is to bring some reassurance to the sick and to the well that a response will exist to a medical need. This reassurance is clear in cases in which one expects that one will want medical care. Could it include cases in which medical care is not wanted because the patient is unaware of the need? In one survey,[10] the number of lay people who agreed that physicians should intervene in situations in which their unsolicited help would be useful was substantial. This function of medicine seems to exist in cases in which, because of lack of information or awareness, medical help is not sought.

Respecting a request to be left alone from a patient who may be making an irrational choice potentially lessens the protection that this individual could receive. In addition, doing it repeatedly weakens the function of medicine as a safety net. Protecting this function is important. If the risk to competent patients is small, protecting the safety net could require an obligation on the part of the patient to explain the reasons for refusing beneficial treatment. If following the patient's wishes placed the patient at significant risk, the patient would have a duty to explain them before they could be followed. This would be an obligation to the patient's community, as a contribution to maintaining the safety net. More important, it would not require that the patient explain the reasons to a clinician. As long as the patient made them intelligible to someone who could determine whether the patient was irrational, this would suffice. The assessment of decision-making capacity has been delegated to physicians not because it is necessarily a part of medicine but because they are perceived as being in a better position to do it. This is not always the case. Certain skills that physicians acquire can improve this assessment, but it certainly cannot be done without the necessary trust and the capacity to enter into a dialogue with the patient. This could sometimes mean that others are in a better position. In cases in which the added risk was significant, if no assessment could be made by anyone, maintaining the safety net would require that the patient be treated as though the patient lacked decision-making capacity. Clinicians, however, would need to have failed in establishing a dialogue with the patient, and failed in finding someone who could do so, before treating the patient in this way.

The law broached this subject in one English case of treatment refusal. The judgment stated that "in cases of doubt where the withholding of treatment would lead to serious damage to the patient's health or even death, that doubt should be resolved in favor of the preservation of life; if the individual wanted to override the public interest in preserving life, they must do so in clear terms."[11(p11)] This decision has legal force only in England. It rests on the argument that the preservation of life is a public concern that can only be trumped by a choice made by a clearly autonomous patient. Where this is accepted, it could be an added reason to require that decision-making capacity be clear in cases in which life-saving treatment was being refused by a patient who was not terminally ill.

Risks to Competent Patients

What is risked if clinicians treat patients as if they lacked decision-making capacity when they refuse beneficial treatment without explaining why? The concerns are that autonomous choice risks being trumped by public concerns and that physicians could be acting in a paternalistic way. The kind of practical scenarios to which this could lead, however, are not as worrying as it first seems.

A patient who is competent to refuse treatment would likely be competent to refuse to explain why, if the patient was sufficiently informed about both. If the patient were competent, the patient's refusal to explain would be an informed refusal. The patient could be informed that the unexplained choice could not be viewed in the same way as it would have been if the patient had explained the reasons for it. If it was made clear that this stems from a concern for those who do not have an adequate understanding of their situation, it seems likely that at least some patients would find it reasonable. Giving this explanation would also make it clear that the clinician was not establishing that the patient was incompetent, which could be inaccurate and insulting. Rather, clinicians should make it clear that they are merely too uncertain to be able to follow the patient's stated choice, because it puts the patient at risk. Furthermore, the patient would not be under an obligation to explain the reasons to a specific person. Whoever the patient trusted most could be appropriate.

This position does seem to weaken the presumption of capacity.[12] However, requiring that competent patients explain their reasons does not question the presumption of capacity itself. The burden would still be on the clinicians to do all they could to clarify the patient's capacity, including searching for someone the patient trusts enough to talk to.

The main risk to competent patients, then, is that of having to give reasons to someone they would select themselves if their choices are to be followed. This does not seem to be an excessive burden. Protecting patients who do not have an adequate understanding of their situation can reasonably require that patients who refuse beneficial treatment explain their reasons before their wishes can be followed, when following their wishes would place them at significant risk.

USING THIS APPROACH

When clinicians have done their best to obtain their patient's trust and engage in a dialogue with the patient, and when they have tried unsuccessfully to find others with whom the patient would agree to talk, they should assess the risk to the patient if the patient's wishes are followed. If the risk is significant, they should choose

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a course of action as if the patient were incompetent. They should also explain this to the patient as if the patient were competent. This approach does not make such situations easy. It removes the insoluble problem of decision-making capacity assessment, when it is really insoluble. However, treating the patient as though the patient were incompetent means that clinicians must make their decision based on a proxy's substituted judgment, or based on what is viewed as the patient's best interest. It does not mean that treatment should be enforced, or that attempts at discussion should stop. Even when treatment itself would be beneficial, enforcing the same treatment may, on balance, be harmful. Respecting a patient's stated choice carries value even when decision-making capacity is clearly absent.[13] The same would apply to patients who refuse to explain their reasons, were they to be treated as if they were incompetent. If the urgency of a capacity assessment is removed, meaningful discussion of other, perhaps easier, issues could even facilitate establishing a dialogue in cases in which it seemed impossible.

In the case described, this view would allow the physician or other members of the health care team to continue the discussion with Irene despite her stated refusal that they should do so. It would put a heavier burden on the team to find someone whom she trusted enough to discuss her reasons with. Here is one of the ways this case could continue.

The physician tries to think of alternatives. Home care services are available, but their resources are limited and the risk of discharging Irene with no other help could still be significant. The physician asks Irene if there is anyone else she would be willing to discuss this with. The physician explains that, although it is important to respect her wishes in deciding what to do, it is also important that people who do not understand their situation well enough to make choices be protected. Irene says that she understands and will call a neighbor. Later, this neighbor calls the physician. "Irene is afraid," she says. "She thinks that if she tells you that she cannot sleep away from home, you will not accept to discharge her. But this is very important to her. Can you arrange something? I could help for a few days too." When she is told that she can go home, Irene agrees to stay until the next day to allow home care services to be put in place. She is discharged from the hospital the following day.

Sometimes, refusal of care can arise from a sense of desolation.[14] Searching for people whom the patient trusts could help correct some situations in which social isolation leads to refusal of care. It is also dangerous to make it too easy to trump the obligation of clinicians to help those in need of medical care.[15] The threshold should be kept at a stricter level than one at which simple silence would make it obligatory to let sick individuals die if they had voiced an unexplained refusal to be treated.

CONCLUSIONS

Patients who refuse to explain the reasons for their choice make assessment of their decision-making capacity impossible. I have argued that if a patient who refuses beneficial treatment also refuses to explain why, clinicians should first do their best to engage in a dialogue with the patient, and to try to find others with whom the patient would agree to discuss the reasons. If this is unsuccessful, clinicians should assess the risk to the patient if the patient's wishes are followed. If this risk is significant, they should choose a course of action as if the patient were incompetent. The reasons for choosing this course of action should be explained to the patient as if the patient were competent. This approach neither sacrifices respect for the patient's choices nor care for the patient's best interest. It permits satisfactory resolution of difficult situations with the least possible harm. By outlining a framework for decision making in defined situations, this approach could help prevent decision making from being frozen by the impossibility to assess capacity. More important, it gives clinicians who face such situations the possibility of persisting in their efforts to establish a conversation with their patients.

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