What Part of "No" Don't You Understand?

Patient Refusal of Recommended Treatment in the Emergency Department

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Abstract

Patient refusal of indicated medical treatment, especially when the treatment would be life sustaining, presents all physicians, especially emergency physicians, with the responsibility of determining whether the patient has the capacity to refuse treatment, and whether the patient's refusal is informed. These two crucial questions present a number of dilemmas for physicians who may have no prior relationship with that particular patient. The ethical and legal principles for determining decision-making capacity and assuring that refusal is informed are described, and an algorithm for responding to patient refusals is presented.
Key Words: Informed consent, informed refusal, life-sustaining medical treatment, decision-making capacity, emergency treatment, emergency privilege.

One of the most vexing problems for emergency physicians occurs when a patient comes to the emergency department but refuses treatment that, in the emergency physician's opinion, is either indicated or, in some cases, necessary to treat life-or-limb-threatening emergencies. The immediate problem is whether or not to honor that refusal. Such decisions, which have to be made in less than ideal circumstances, can have drastic implications for the health or life of the patient. In some cases, drastic measures to coerce the patient to be treated against his or her expressed refusal are necessary (1). These dilemmas are fraught with ethical and legal implications (2).

The emergency department environment is unique. It is open to all who have emergent or urgent medical problems, and it is required by federal law to evaluate the patient and, if the patient has an emergent medical condition, to treat the emergency or to stabilize and transfer the patient to a facility that can definitively treat the patient (3). The emergency department is also the place where patients who are indigent or uninsured may seek treatment for medical conditions. Such patients may have either avoided prior medical treatment or have been turned away from outpatient treatment for financial reasons. Patients often seek care at the closest medical facility, and the emergency physician is usually not chosen by the patient. Typically, there has been no prior doctor-patient relationship and thus no previous opportunities to build trust. The patient is frequently brought to the emergency department involuntarily by ambulance, either at the insistence of others, such as family members or friends, or in other cases, at the behest of the police at a crime scene. The patient has often experienced a sudden change in health status and may be in pain, be anxious, or have an altered mental status. Decisions must be made quickly, often with incomplete information, since the patient's medical records may be unavailable (4). The emergency environment may also be characterized by a lack of patient privacy. Emergency departments are often constructed as arenas, with bays of beds separated by curtains to allow the maximum visual-

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ization of many patients. The corresponding openness results in interactions between physician and patient being visible and audible by other staff and, at times, other patients (5, 6).

It is in this less than ideal environment that emergency physicians have to obtain consent to treat patients and to evaluate patients who refuse recommended medical treatment, including life-sustaining medical treatment. The ethical and legal requirement of informed consent has long been a mainstay of the relationship between physician and patient. Consent is required for procedures, testing, treatment and research, even if the procedure is essential for the patient (7). Informed consent in most circumstances need not be accompanied by written documentation. Verbal informed consent may be adequate, although these patients will be asked to sign a general consent for treatment, and the law or hospital policy may require that some tests and procedures be accompanied by the informed consent and signature of the patient or patient's representative.

The elements of information that must be disclosed include the risks, benefits, and alternatives, including the anticipated results of no treatment (8). There are two legal standards for disclosure of information. The traditional standard mandates that the physician disclose to the patient what the average prudent physician would disclose to the patient. This standard was set by the medical profession and is known as the "professional standard." A majority of the states now require that the information that must be disclosed conform to a standard set by what the "objective patient" would find material to the decision of whether or not to undergo the procedure. This is known as the "objective patient standard" (9). Under the professional standard, expert witness testimony is required to establish whether a physician met the standard or not. Under the objective patient standard, the jury, without expert testimony, determines whether or not the physician met the standard. The professional standard might appear to be a higher hurdle for a plaintiff-patient, since physicians might be less likely than a jury, in retrospect, to find a particular piece of information necessary to disclose. However, the increased willingness of physicians to testify as experts for the plaintiff has led to less of a practical difference between the two standards.

Informed consent, however, is not required under all circumstances. There are two well-recognized ethical and legal exceptions. The first is the emergency exception to informed consent, known in the law as the "emergency privilege." Patients may be treated without their informed consent when these criteria are fulfilled: The patient lacks decision-making capacity (e.g., is unconscious); no one is available who is legally authorized to act for the patient. Time is of the essence in that there is a serious risk of bodily injury or death. Given the serious risk, it is assumed that a reasonable person would consent if he or she were able to (10).

The emergency privilege allows emergency physicians to act in emergencies to treat patients without consent in many clinical situations, for example, when comatose patients are brought in critical condition to the emergency department. Emergency physicians are usually aware that this exception gives them permission to treat patients without consent but often do not recognize how circumscribed it is. For example, the emergency privilege does not allow emergency physicians to treat competent patients with emergent conditions who refuse treatment, or incompetent patients who have a legal representative authorized to accept or refuse recommended medical treatment.

The second exception to informed consent is known as the "therapeutic privilege," which allows treatment without full disclosure to the patient of the medical circumstances necessitating treatment. This exception is allowed only when full disclosure of the patient's medical condition would have such an adverse effect on the patient that it might render him or her unable to make a medical decision or might cause psychological or even physical injury (for example, extreme distress, depression, thoughts of suicide). In such cases, reasonable discretion must be used in the manner and extent of the disclosure, and full disclosure must be made at the first opportunity, when the patient would no longer be so distressed by the information that he or she could not make a medical decision. This exception, although it has legal precedent, should rarely be invoked, since its routine use would undermine the autonomy of patients (11).

It is an obvious corollary that since consent is needed to treat patients even when the treatment is medically necessary, patients also have the concomitant right to refuse treatment. This right to refuse medical treatment extends to the right to refuse even life-sustaining medical treatment. The right of a guardian to refuse treatment for a patient was first recognized by a state court in the case of Karen Quinlan (12), and subsequently recognized as a federal 14th Amendment liberty interest in the case of Nancy Cruzan (13). Patients with a terminal condition have the right to refuse medical treatment, but patients need not have a terminal condition to refuse life-sustaining medical treatment (14). Elizabeth Bouvia, a woman with cerebral palsy, was recognized by a California appellate

court to have the right to refuse nutrition and hydration (15), and state courts have recognized the right of competent Jehovah's Witness patients to refuse life-sustaining medical treatment in the form of blood transfusions, even if that refusal would result in the patient's death (16). One of the most vexing ethical conundrums for emergency physicians occurs when a patient who does not have a terminal illness refuses life-saving treatment for what appears to be a very treatable—and reversible—condition. The emergency physician's predisposition by training, and often by temperament, is to intervene to preserve life. It is often counterintuitive to emergency physicians that patients should have the right to refuse well-intentioned life-sustaining treatment. In fact, emergency physicians often express the opinion that a good medical outcome should trump a patient's refusal. Emergency physicians often cite a legal canard that "No one has ever been successfully sued for erring on the side of preserving life," even in the face of patient refusal. If this was ever true, it is no longer so. Life-saving treatment against a competent patient's refusal may result in a suit for battery, medical negligence, and lack of informed consent (17).

A patient's refusal of treatment does not end the physician's responsibilities. Patients who refuse medical treatment have the right to be informed of the consequences of their refusal (18). This can be difficult to do in the emergency department, since patients who refuse medical treatment are often unwilling to engage in further conversation about their refusal and may feel that any further information is merely being used to pressure them into acceding to the physician's recommendation. But even informing the patient about the consequences of refusal does not end the physician's duties.

Since patients who have the capacity to make medical decisions have the right to refuse treatment, even life-sustaining medical treatment, and the consequences of such refusal can be grave, the determination of whether the patient is able to make decisions about his or her medical care is of crucial importance (19). Though the term "competence" is used in common parlance to refer to a person's ability to make important personal or financial decisions, and in legal contexts to refer to the legally recognized ability of an individual to make decisions about his or her person or property, it is recognized that there are circumstances in which patients who have not been found by a court to be incompetent are nonetheless unable to make medical decisions (e.g., the competent person who is temporarily unconscious due to an anesthetic). Conversely, there are persons who may be legally determined to be incompetent but may nonetheless be able to express their wishes to a physician concerning medical procedures (20). Since the ability to make decisions about medical care may differ from competency according to legal determinations, "medical decision-making capacity" has become a preferred term when considering the ability of a patient to make a specific medical decision at a specific time.

Medical-decision-making capacity is present when the patient is able to understand information about the medical condition and its consequences, to reason and deliberate about the various choices, to make a choice consistent with his or her values and goals, to communicate this choice to the physician, and to maintain this choice consistently over time. Any break in this chain of elements constitutes a lack of decision-making capacity (21).

Thus, a patient lacks decision-making capacity if he or she cannot understand the information needed to make a medical decision, reason about the information in light of personal values and goals, or reach a decision and communicate it clearly and consistently.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research further delineated the nature of decision-making capacity, recognizing that it is dependent upon the individual abilities of the patient, the requirements of the task at hand, and the consequences of the decision. When the consequences of the decision are substantial, there is a greater need for certainty of the patient's decision-making capacity (22). Thus, a physician who encounters a request from a patient to forgo a life-saving intervention has a duty to determine whether the patient has the capacity to refuse such treatment.

Decision-making capacity is not necessarily established by a patient merely expressing a preference, by the content of the decision conforming to a socially determined "objectively correct" standard, or even by its concurrence with the physician's recommendation. There are some patients who are obviously incapable of making medical decisions: infants, young children, patients who are comatose or severely mentally handicapped. Whether or not other patients have decision-making capacity may not be so straightforward.

An assessment of decision-making capacity must assess the patient's ability to (a) understand, including comprehending information and appreciating consequences; (b) evaluate, comparing risks and benefits, and to make a rational and consistent choice; and (c) communicate that choice. The pa-

tient's ability to weigh choices against personal values and consistency of choice must be tempered by the fact that some patients may change their values and their decisions over time, and others may make decisions that take into account their family relationships and religious, philosophical, cultural and societal values.

A traditional test used to determine a patient's mental status is the Mini-Mental Status Exam (MMSE), which tests orientation, memory, attention, and reasoning ability (23). But this test of mental status may not address critical issues of decision-making capacity, namely the ability to weigh personal values and to make decisions on the basis of those values (24). The ability to assess decision-making capacity should be a skill that is a routine part of emergency medical practice, although more complex evaluations may require consultation with a mental health professional (25). Nonetheless, many of these evaluations must be done under urgent or emergent circumstances. Physicians routinely make these determinations on an informal basis during their conversation with the patient.

It has been observed that questions of patient decision-making capacity typically arise when a patient chooses a course, often a refusal of treatment, that goes against the course that the treating physician finds most reasonable (26). While it is true that physicians generally do not question the decision-making capacity of patients who follow their recommendations, for emergency physicians, patient refusal of life-sustaining medical treatment may have fatal consequences. The determination of decision-making capacity is therefore critical. Importantly, it may not follow that if one has the capacity to consent to treatment, one must also have the capacity to refuse treatment. The reason for this inequality is that concern for the patient's well-being must be balanced against respect for the patient's self-determination. If the likely consequences to the patient's well-being are very harmful (e.g., disability or death) if the patient refuses, and very beneficial if the patient accepts treatment, it has been argued that the patient needs a higher level of decision-making capacity to make the negative decision. And if the treatment would be beneficial to the patient, the level of decision-making capacity to accept it need not be as high (27).

Patients who are mentally ill, drug dependent or developmentally disabled, or who manifest behavior or statements that evidence a substantial probability of harming oneself or others may be emergently detained for treatment under statutory authority. And patients whose judgment is impaired and who are at risk of physical impairment or injury due to that impairment (e.g., patients with advanced dementia) may also be detained and treated under statutory authority pending guardianship.

More challenging are those patients who do not appear to be mentally ill, impaired by drugs or alcohol, or by dementia, and yet express a seemingly irrational choice by refusing needed life-saving treatment. These patients may express a bias toward the present and near future over longer-term goals; for example, a patient may wish to put off treatment of a heart attack in order to go home to take care of a pet. They may also demonstrate an unrealistic attitude toward risk, weighing the small risks of anesthesia for surgery for appendicitis as greater than the actually extremely higher risks of a ruptured appendix. Another type of irrational choice occurs when patients' fear of pain or the medical experience outweighs the benefits of treatment, for example, in the case of a patient who is undergoing a severe and possibly fatal allergic reaction but refuses treatment because of a fear of needles. Finally, there is a seemingly irrational choice involved when the patient views what will be lost as much greater than what will be gained, e.g., the young patient who refuses the needed appendectomy because a scar would interfere with a future career in modeling (28). These patients present serious dilemmas for emergency physicians who wish to balance their patients' right to be free from unwanted medical care against their need for emergency intervention. Situations such as these may call for the assistance and expertise of mental health professionals.

Common pitfalls in determining decision-making capacity have been identified (29) and grouped into a list of ten so-called "myths" about decision-making capacity (30):

1. Decision-making capacity and legal competency are equivalent. This myth is rebutted by the recognition that on the contrary, as discussed above, they are different categories, though they may often overlap.
2. A patient who refuses to follow medical advice obviously does not have decision-making capacity. On the contrary, patients who possess decision-making capacity have the ethical and legal right to refuse even life-sustaining medical treatment.
3. A patient who follows medical advice obviously possesses decision-making capacity. Though this may often be true, patients who lack decision-making capacity, such as patients with severe dementia, may be very compliant patients.
4. Decision-making capacity is an "all-or-nothing" ability. That is, a patient who cannot make

one type of medical decision cannot make any medical decisions. On the contrary, decision-making capacity is dependent upon the decision to be made. A patient who is unable to make a decision about a life-threatening problem might be able to make a decision regarding his or her preference as to how a medication should be administered.

5. A patient who has some cognitive impairment is therefore unable to make any medical decisions. Both legal precedent and geriatric practice contradict this myth (31). Patients may have varying degrees of cognitive impairment that may or may not affect decision-making capacity.
6. Once a patient is incapacitated, the incapacity is permanent. Not true. For example, a patient incapacitated by intoxication will probably recover decision-making capacity, and even patients who have dementia may have fluctuating periods when they have the ability to make some medical decisions (32).
7. Patients who lack information to make a decision therefore lack the capacity to make medical decisions. On the contrary, the ability to understand information is central to decision-making capacity, but a lack of information does not imply a lack of ability to make decisions.
8. The fact that a patient has a psychiatric diagnosis means that the patient is not able to make medical decisions. Not so. A patient who has a diagnosis such as schizophrenia may well have impaired decision-making capacity for certain periods of time, but may be able to make medical decisions during others despite the underlying psychiatric condition.
9. Patients who are involuntarily committed for mental health treatment are not able to make medical decisions. On the contrary, many states' laws allow patients who are involuntarily committed to make some medical decisions and even to refuse psychotropic medications unless they are an imminent danger to themselves or others.
10. Only mental health experts may assess decision-making capacity. On the contrary, as noted above, all physicians, especially emergency physicians, should have the ability to assess decision-making capacity. Mental health expertise may be necessary in more complex cases.

Once a patient has been determined to lack decision-making capacity, emergency physicians are charged with making decisions in the best interest of the patient or according to the patient's preferences, if the patient has expressed treatment preferences before becoming incapacitated, for instance, in an advance directive. The emergency physician should also seek to identify a decision maker for the patient, such as a guardian, health care agent, or other surrogate such as a spouse, family member, or close friend.

Even with these guidelines, several additional problems face emergency physicians when encountering a treatment refusal. What words or actions constitute a refusal by a patient with decision-making capacity? How consistent must the patient's refusal be? What level of certainty that the patient is able to make the decision to refuse life-sustaining medical treatment should be required before a patient may choose a course that risks almost certain death? And to what degree may liberty be restricted until a determination of decision-making capacity is made?

The following algorithm may help in considering how to address patients who refuse medically indicated treatment.

Algorithm for Patient Refusal of Medically Indicated Treatment

1. Does this patient have decision-making capacity?

- If yes, the patient may refuse even life-sustaining medical treatment

  Be sure the patient understands the risks and consequences of refusal and accepts those risks, utilizing careful documentation and a witness to the discussion when necessary. If the decision entails life-threatening consequences, consider the role of the patient's family or friends in helping the patient weigh the decision carefully and asking the patient's permission to involve them in the discussion.

- If no:
  2. Is the non-decisional patient under legal protection such as emergency mental health detention or court order?
     - If yes, treat within the constraints of the legal restrictions
     - If no:

  3. Does the non-decisional patient have a legally authorized decision maker, a document indicating a power of attorney for health care, or a living will that expresses the patient's preference?
     - If yes, is the decision maker available?
       - If yes, consult the decision maker

   - If no, and this is not an emergency, seek the decision maker
 - If there is no legally authorized decision maker or document and this not an emergency, seek a new legally authorized decision maker such as a guardian

4. Is this a bona fide emergency (i.e., a life- or limb-threatening condition)?
   - If no, seek a legal decision maker
   - If yes, (i.e., there is a life or limb threat AND time is of the essence AND no legally authorized decision maker is available AND a reasonable person would consent):
     - Act in the best interest of the patient and concurrently seek a legally authorized decision maker

- If the physician is unsure whether the patient has decision-making capacity:
  5. Will the patient allow a determination of decision-making capacity?
     - If yes, determine decision-making capacity by evaluating the patient's ability to understand information, evaluate the information and communicate a decision
     - If no, weigh the need to ascertain the patient's decision-making capacity against the harm of allowing the patient to refuse without a determination of capacity.
       - If there is a need to determine whether the patient is decisional, use the least restrictive and least invasive means of determination, emphasizing the need to the patient to determine decision-making capacity and concern for the patient's best interest. If necessary and if time allows, seek professional mental health expertise.

Patient refusals of indicated medical treatment, especially life-sustaining medical treatment, present emergency physicians with the responsibility of determining whether the patient has the decision-making capacity to refuse treatment and whether the patient's refusal is informed. This responsibility must be balanced against the patient's ethical and legal right to refuse life-sustaining medical treatment. The necessity of determining decision-making capacity and providing information to the patient about the consequences of refusal is central to making certain that patient autonomy is respected and that patients who cannot make autonomous decisions are protected from harm. When a patient inexplicably refuses indicated medical treatment, especially life-sustaining medical treatment, the discussion—and the need for careful consideration by the emergency physician of the patient's decision-making capacity—has not ended, but has just begun.

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