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When Patients Refuse Treatment

Health care professionals are understandably concerned when patients refuse recommended treatments. How should practitioners respond when a patient declines an intervention that practitioners believe is appropriate and needed? The answer to that question depends on both the patient's decision-making capacity and the particular circumstances of the treatment decision.

Refusing Treatment

The right to refuse unwanted treatment, even potentially life-saving treatment, is central to health care ethics. Practitioners should take care *not* to assume that a patient who refuses recommended treatment lacks decision-making capacity.[1] A capacity assessment is appropriate if the practitioner has reason to believe the patient might lack one or more of the components of decision-making capacity.

When decision-making capacity is not in question, practitioners must respect the patient's decision to decline an intervention, even if they believe the decision is not the best one that could have been made.

However, this does not mean that health care professionals should never question the patient's decision, or never try to persuade the patient to accept treatment. For example, by exploring the reasons for refusal with the patient, a practitioner might learn that the patient simply needs more information before deciding to proceed.

The professional ethical ideal of shared decision making calls for active, respectful engagement with the patient or surrogate. As a prelude to exploring a patient's refusal of recommended treatment, practitioners should clarify the patient's (and/or surrogate's) understanding of the clinical situation and elicit his or her expectations about the course of illness and care.[2,3,4] Practitioners should clarify the goals of care with the patient or surrogate, address expectations for care that may be unrealistic, and work with the patient or surrogate to prioritize identified goals as the foundation for a plan of care.[3,4]

Asking in a nonjudgmental way, "What leads you to this conclusion?"[2] can then help the practitioner to understand the reasons for the patient's decision to decline recommended treatment. It can also help to identify concerns or fears the patient may have about the specific treatment that practitioners can address. The aim should be to negotiate a plan of care that promotes agreed on goals of care.

Addressing Patients' Refusal of Treatment

In responding to a patient's refusal of recommended treatment, practitioners should:

Clarify the patient's (or surrogate's) understanding of the clinical situation and why this treatment is recommended

Clarify and come to mutual understanding of goals of care

Clarify reasons for refusing treatment:
- *validate concerns*
- *explore fears*

Negotiate a solution that promotes the agreed on goals of care

Adapted from Arnold R. What to do when a patient refuses treatment.[3]

Resisting Treatment

Health care professionals face different concerns when patients who lack decision-making capacity resist treatment for which their authorized surrogates have given consent. When a surrogate consents to treatment on behalf of a patient who lacks decision-making capacity, practitioners are authorized to carry out the treatment or procedure even if the patient actively resists. In such cases, treatment is not being administered over the patient's re-

fusal because the surrogate has taken the patient's place in the process of shared decision making and exercised the patient's decision-making rights.

However, practitioners should still be sensitive to patients who resist treatment. They should try to understand the patient's actions and their implications for treatment. Practitioners should ask themselves why, for example, a patient repeatedly tries to pull out a feeding tube. Is the tube causing physical discomfort? Is the patient distressed because he or she does not understand what is happening?

Resistance to treatment should prompt practitioners to reflect on whether the treatment is truly necessary in light of the established goals of care for the patient, or whether it could be modified to minimize the discomfort or distress it causes. For instance, a patient may resist treatment via one route of administration but not another.

Practitioners should also be alert to the implications of the patient's resistance for the judgment that he or she lacks decision-making capacity. In some cases, resistance to treatment may be an expression of the patient's authentic wishes. Decision-making capacity is not an "all or nothing" proposition. Rather, decision-making capacity is task specific. It rests on being able to receive, evaluate, deliberate about and manipulate information, and communicate a decision, which can vary considerably with the decision to be made.[5] A patient may have capacity to make a simple decision but not a more complex one.[1] For example, a patient may have capacity to consent to insertion of a feeding tube but lack capacity to consent to chemotherapy.

When a patient resists, surrogates, family members, or friends may be able to shed light on the patient's actions and help practitioners identify ways to provide treatment that are less upsetting for the patient. For patients with fluctuating capacity, it may be possible to explore concerns directly with the patient during lucid moments.[6]

Patients who resist treatment present unique challenges for health care practitioners. The root cause of the resistance should be explored, as well as other clinically acceptable alternatives to the proposed treatment.

Understanding Resistance to Treatment

When a patient who has been judged to lack decision-making capacity resists treatment, practitioners should think carefully about the possible meanings of the patient's actions. They should ask themselves:

Why is the patient resisting this intervention?

- *Is the intervention causing physical discomfort or psychological distress?*
- *Are there ways to modify the intervention that would minimize the patient's discomfort or distress?*

Is it essential to provide this intervention to achieve important goals of care, or, given the discomfort or distress it causes, could it be postponed or foregone entirely?

Might the patient's resistance in fact be an expression of his or her authentic wishes?

- *Might the patient have the capacity to make an informed decision about this particular intervention?*
- *Should we re-evaluate our assessment of the patient's overall decision-making capacity?*

References & Resources

1. National Ethics Committee. *Ten Myths About Decision-Making Capacity*. September 2002.
2. Arnold R. Fast Fact and Concept #056: *What to do when a patient refuses treatment*, End-of-Life Physician Resource Center (EPERC). Posted November 2001.
3. Bailey FA. *The Palliative Response*. Birmingham, AL: Menasha Ridge Press; 2003.
4. Weissman D, von Gunten C. Fast Fact and Concept #023: *DNR orders in the hospital–Part 1*. End-of-Life Physician Resource Center (EPERC). Posted September 2000.
5. Arnold R. Fast Fact and Concept #055: *Decision making capacity*. End-of-Life Physician Resource Center (EPERC). Posted November 2001.
6. High DM. Families' roles in advance directives. Hastings Center Report 1994;24(6): S16–S18.