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#### When Can Physicians Say "No" to Families and Patients?

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# When can physicians say "no" to families and patients?

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#### CLINICAL DECISIONS

INTERACTIVE AT NEJM.ORG

## Care of an Unresponsive Patient with a Poor Prognosis

Arthur S. Slutsky, M.D., and Leonard D. Hudson, M.D.

This interactive feature addresses the diagnosis or management of a clinical case as informed by research published in this issue of the Journal. A case vignette is followed by specific clinical options, none of which can be considered either correct or incorrect. In short essays, experts in the field then argue for each of the options. In the online version of this feature, available at NEJM.org, readers can participate in forming community opinion by choosing one of the options and, if they like, providing their reasons.

#### CASE VIGNETTE

A 56-year-old homeless man was found having a seizure and was transported to the hospital. He was found to have a subarachnoid hemorrhage and acute hydrocephalus. He underwent intubation, and mechanical ventilation was started. A shunt was placed to relieve the hydrocephalus; cerebral angiography revealed a ruptured aneurysm of the

as "a fighter" who would want aggressive care until the prognosis was much more certain.

Supportive care, including mechanical ventilation, was continued for the next 3 weeks, without any clinically significant change in the patient's neurologic state. During this time it was discovered that the patient had a very close relationship with a counselor at a homeless shelter with whom

### Case

- 56 y.o. with ruptured aneurysm of the anterior communicating cerebral artery; unruptured aneurysm of the posterior CA
- 50% chance of bleed with clipping; surgery "high risk"
- 90% chance of persistent vegetative state; 10% chance of recovery to severe disability
- No response after 3 weeks of ICU treatment
- "large duodenal ulcer with fungating edges partially obstructing the gastric outlet"
- Son demands "full aggressive-care measures...including clipping of the aneurysm".



### Comments

 "At the present time, it would seem as if there is little meaningful chance of recovery given the lack of improvement despite several weeks of aggressive support. However, the son would be the next legal surrogate, and does have the right to continue care." [Comment ID: C583F1]

 "Legally speaking the son is in charge of the decisions for the father, and his word is ultimately final.
 Despite any other solutions for the situation, pragmatic or not, we are all bound by the law first and foremost." [Comment ID: 4FCC23]

## Questions

- 1. Whether, and if so on what basis, may a physician refuse to provide treatment demanded by a patient or his or her legal surrogate?
- 2. Are their circumstances in which a physician is obligated to refuse to provide demanded treatment?

# Rise of autonomy

- Birth of the bioethics movement in the 1960s corresponded with the patient rights movement
- Reaction against a model of decision making in which physicians largely directed the care which their patients would receive
- Patient autonomy became widely accepted by ethicists and physicians alike.

## Delimiting autonomy

- Prominent legal cases in the 1990s (Wanglie; Baby K) highlighted patient demands for treatment
- Autonomy suggests that a patient not only has a right to refuse unwanted treatment, but also has a right to demand wanted treatment
- Task was understood as one of settling the boundaries of patient autonomous choice.

## Futility

- "Futility is a professional judgment that takes precedence over patient autonomy and permits physicians to withhold or withdraw care deemed to be inappropriate without subjecting such a decision to patient approval."
  - Schneiderman LJ, Jecker NS, Jonsen AR. *Annals of Internal Medicine* 1990; 112: 949-954.

# Two types of futility

#### • Quantitative futility:

- "[W]hen physicians conclude (either through personal experience, experience shared with colleagues, or consideration of reported empirical data) that in the last 100 cases, a medical treatment has been useless."

#### Qualitative futility:

- "In keeping with the qualitative notion of futility we propose that any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care should be regarded as non-beneficial and, therefore, futile."

# Fall of futility

- The definition of quantitative futility seems arbitrary
- The definition of qualitative futility seems to obscure values disputes between patient and physician as to what sort of life is worth living
- Without a clear legal foundation, courts are reluctant to endorse the concept.
  - Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. N Engl J Med 2000; 343: 293-296.

## Procedural approaches

- Extra-judicial mechanisms to resolve conflict involving end of life care
- Ethics consultation; patient transfer
- If no resolution, then futile treatments may be stopped
- Questions:
  - Do all disputed demands for care need to be submitted to such a mechanism?
  - Given that transfer is unlikely, will the courts uphold stopping treatment in the absence of resolution?

## Tort law

- Can a reexamination of the principles of tort law provide further clarity on treatment demands?
- Review of legal cases and relevant statutes in Canada, the US, and the UK
- Results presented here are provisional and do not address issues regarding application of our finding to practice

# Nature and scope of consent

- The right to informed consent protects the autonomy of patients in two ways
  - It requires physicians to respect patient choice whether to submit to medical intervention at all
  - It requires physicians to facilitate and respect patient choice amongst medical interventions consistent with competent care.
- Tort law has never recognized a right to treatment as such, let alone a right to demand particular treatments.

## Negligence

- When a physician accepts a patient for care, the care provided must be competent in light of professional standards (duty of care)
- These are informed by custom within the medical profession and the evidence upon which custom rests
- Requires careful exercise of professional judgment. Furthermore, the burden of judgment is borne by the treating physician.
- Consent is not a defense to liability for substandard care.

## Consent and duty of care

- The law of informed consent and negligence are reconciled in the recognition that patients have a right to determine the course of their treatment that extends as far but no further than treatment options consistent the physician's duty to render competent care
- A physician may not impose care that she feels is medically necessary
- Likewise, a patient may not demand treatment that the physician considers substandard

## Implications for treatment demands

- The law does not recognize a patient right to treatment as such, let alone a right to demand particular treatments
- The law does entitle a patient who has been accepted by a physician to choose from among treatment modalities consistent with professionally validated standard care.

## Implications for treatment demands

• The physician is entitled to refuse demands for nonstandard treatments, including treatments that have not been validated according to professional standards (e.g., experimental drugs, nonstandard uses of licensed drugs, alternative or complementary treatments) or those that go above the standard of care (e.g., additional care that would not ordinarily be provided as a part of standard treatment).

## Implications for treatment demands

• The physician is obligated to refuse demands for treatment when the provision of such treatment would constitute substandard care (e.g., treatments that have been shown to be harmful, treatments known to be therapeutically inferior to standard treatment options).

## Conclusion

- The debate was wrongly framed from its inception as one of limiting autonomy
- We see it as a challenge involving the accommodation of values, and one that is worked out at the level of legal principle
- Contentious end-of-life cases are multifaceted and involve questions of demands for treatment, quality of life, surrogate decisions, family conflict, scarce resources
- Our analysis clarifies only one of these dimensions