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When values are unknown: Navigating complex medical decisions with professional guardians

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Background

- Decision making is challenging when patients are unable to express their values.
- Surrogate decision-makers ideally make a decision using *substituted judgement*.
- Substituted judgement requires knowledge of a patient that comes from a personal relationship.
- Professional guardians often don't have this knowledge.
- Professional guardians often need to make decisions based on the *best interests* of the patient.
- Professional guardians often elect for non-beneficial disease-directed intervention when they have insufficient guidance from the medical team.

Objectives

1. Identify challenges with complex medical decision making in a patient that has a professional guardian.
2. Describe the ethical principles involved when the decision-maker is a professional guardian.
3. Describe the communication approach to help navigate decision making with professional guardians.

Key Concepts

- Substituted judgment: based on the inferred values and preferences of a patient that comes from a personal relationship
- Best interests: what a “reasonable person” would choose if in the patient’s circumstances

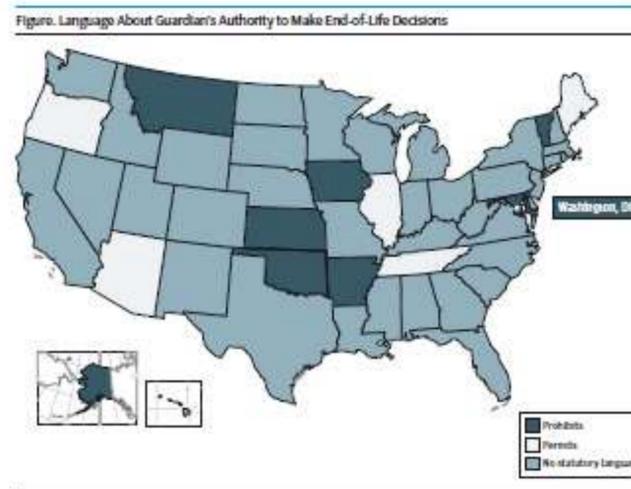
PRINCIPLES OF ETHICS



Case Description

A 60-year-old woman with a history of cerebral palsy, hiatal hernia involving the stomach and colon, dysphagia requiring jejunostomy tube placement, and severe malnutrition was transferred from an outside hospital for surgical hernia repair. The patient lacked decision-making capacity. She had no known family involvement and had a court-appointed professional guardian. She had multiple prior attempts at feeding tube procedures and a complicated exploratory laparotomy at the outside hospital and was still not tolerating tube feeds. Surgery determined that hernia repair would be technically difficult and would require a significant post-op rehabilitation period. Palliative care and ethics were consulted to assist with decision-making. We gathered information about the patient’s life from people at her group home and learned about the risks and benefits from the surgical team’s perspective. We guided the surgical team to think through the benefits and burdens of the surgery and ultimately supported their conclusion that the surgery was not in the patient’s best interests. A clear recommendation not to proceed with the surgery was communicated to the guardian.

Legal Ambiguity



- In most states, it is a myth that the law prohibits a guardian from making-end-of life decisions.
- At the same time, few states explicitly permit a guardian to make end-of-life decisions.
- Case law is scant. However, when the Minnesota Supreme Court took up *In re Guardianship of Tschumy*, it supported a hospital’s petition to authorize the professional guardian of a schizophrenic man with anoxic brain injury to remove life support because it was in the ward’s *best interest*.

Communicating with Professional Guardians

- In communicating with professional guardians, it will often be necessary to explore the patient’s background in order to understand the best interests of the patient before assessing the medical situation requiring a decision.
- Even if family members are not guardians, they may be able to provide insight into the patient’s *endorsed life* values.
- Asking caretakers what a “good day” for the patient looks like can often provide insight into what the patient values.
- One must attempt to understand what the patient is experiencing which requires insight into the *uniqueness* of the patient.
- *Relieving suffering* in all of its forms is of paramount importance, especially when a patient has not provided any indication that they would make decisions that could worsen suffering.
- A thorough assessment of *benefits* and *burdens* of treatment must then be presented in clear terms to the professional guardian.

Conclusion

Gathering collateral information about the patient’s life, using the principle of best interests, and clearly communicating a recommendation aids in decision-making with professional guardians and helps to avoid interventions which are more likely to harm than to benefit a patient.

Bibliography

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- <http://www.husson.edu> (Principles of Ethics illustration)