The Family From Hell

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Objectives

- Recall the contextual fact pattern of "the family from Hell."
- Explain how beginning with good medical facts (as described by Jonsen, Siegler, and Winslade) is critical to the resolution of a clinical ethics dilemma.
- Describe the difference between "substituted judgment" and "best interests" decision making standards.

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Multiple Choice Question

For patients who lack decision making capacity and who have left clear and convincing evidence of their treatment preferences for a given clinical situation, legally authorized representatives should:

a. make treatment decisions for patients they same way they would for themselves
b. use the best interests standard
c. use the shoot from the hip standard
d. use the substituted judgment standard

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Facts

- A.B., is a 62-year-old woman who is a Long John Silvers cook in a small town in Middle Tennessee.
- She is married to a man about 20 years her senior and she is the mother of seven living children.
- The children are in some cases estranged from the parents and each other.

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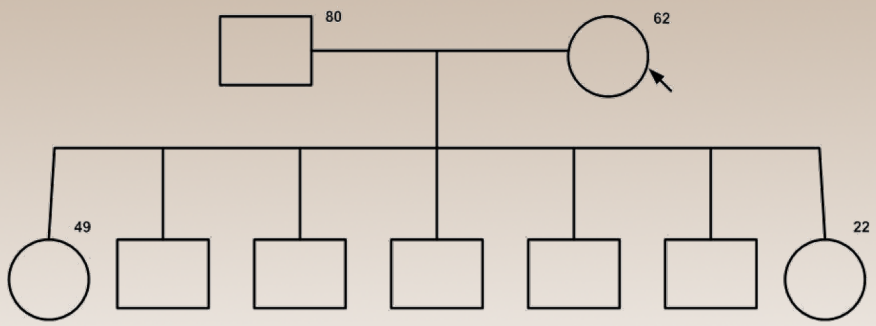
Family pedigree



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Facts [continued]

- The mother begins have curious symptoms: dyspnea, dizziness, occasional nausea, “generally weak and tired.”
- She collapsed at home and via an outlying hospital is transported by emergency medical services (EMS) to St. Thomas Hospital, Nashville, Tennessee.
- She is evaluated by the emergency department team who calls cardiology.

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Facts [continued]

- Within two hours the patient is in the cardiac catheterization suite; the cardiologist found four-vessel-coronary artery disease.
- Within four hours the patient is in the operating room; the cardiovascular-thoracic surgeon bypassed the diseased arteries with grafts (“CABG”).

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Fact [continued]

- The recovery and rehabilitation was prolonged (“four or five times longer than usually the case”).
- The patient never really returned to her baseline after six weeks at home (“she’s just not the same person,” “she has no energy,” “she’s more forgetful than ever before,” “is there something else?”)

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Facts [continued]

- About six weeks after the surgery, the patient collapsed again at home.
- By the time EMS transported her to the outlying hospital emergency department, the patient's right side is paralyzed and the left side is weak, her speech was slurred.
- By the time EMS brought her again to St. Thomas, she was paralyzed from the neck down bilaterally.

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Facts [continued]

- With the aid of radiological imaging and extensive neurological examinations over time, the team diagnosed a basilar artery stroke.
- The neurologists reported the patient's condition as grave yet would not venture much in terms of prognosis except simply repeat reported statistical outcomes.

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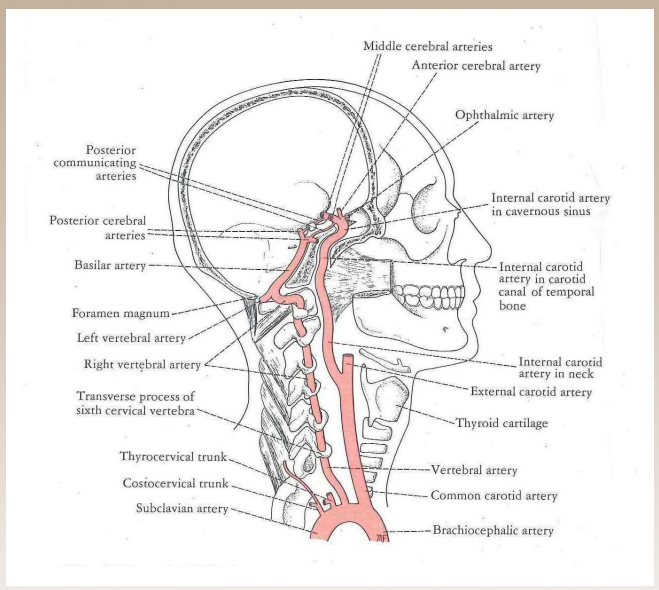

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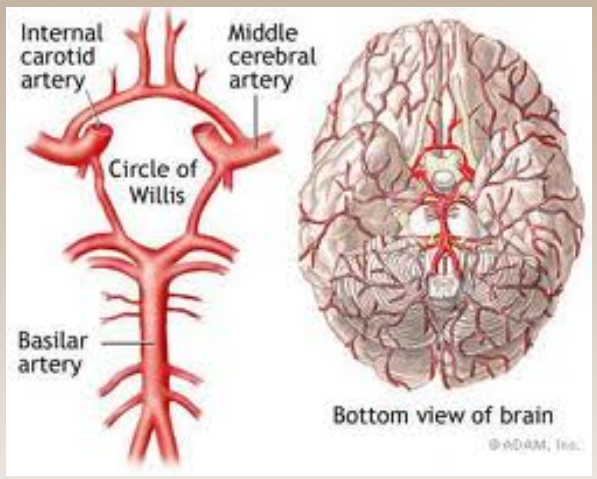

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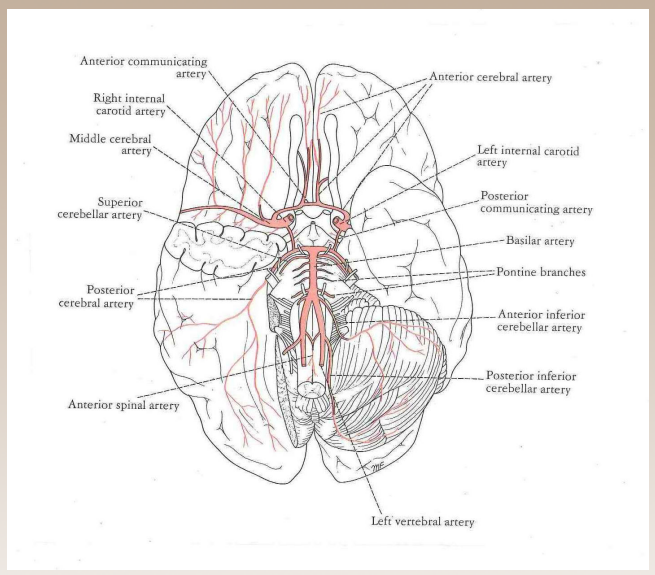

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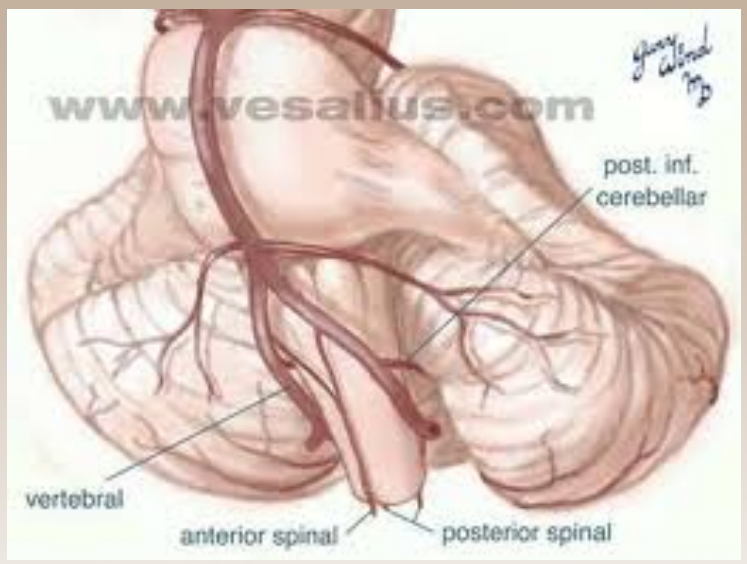

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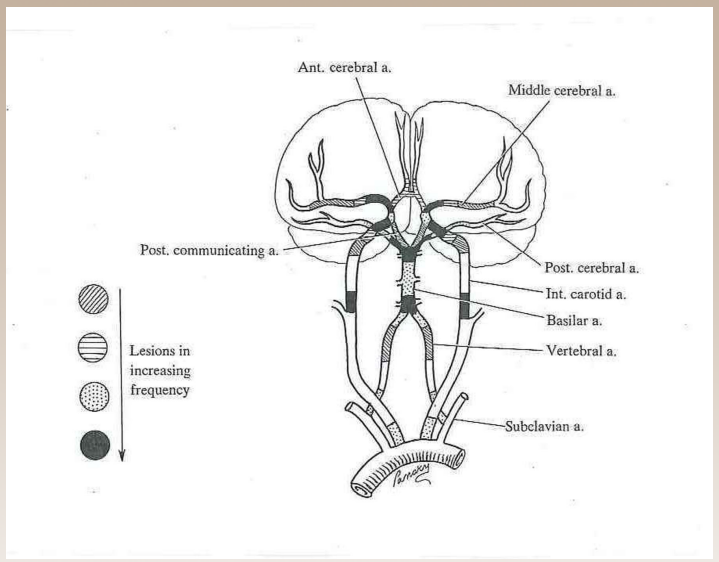

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Facts [continued]

- The patient did not require ventilatory support.
- A nasogastric (NG) feeding tube was placed to begin enteral nutrition.
- The patient became more alert over the next few days but only groaned, ever more loudly, never spoke, as she appeared to arouse more?

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Facts [continued]

- The team assessed the patient's decision making capacity and determined that she lacked capacity to participate in the decision making process.
- The team looked to the family members at the bedside – her middle child Donnie, Donnie's wife, and the second brother's wife - to help make decisions regarding a plan of care.

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Facts [continued]

- For several days, the patient lay paralyzed, moaning, head writhing. She was treated with anxiolytics, antipsychiotics, and pain medicines.
- She was fed via a nasogastric tube.
- She did not require any additional support or treatment.

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Facts [continued]

- The family attempted to comfort the patient as best they could given the circumstances.
- Her husband visited infrequently. He could not drive and a grandson brought him to Nashville. He would not stay long, not venture past the doorway, stand and rock with his hands in his overall pockets. He did not touch his wife.

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Facts [continued]

- The patient was stable. The team began having conversations about moving the patient to a lower level of care.
- To be placed in a nursing home, the patient would require a surgically-placed feeding tube.
- Moreover, the family did agree that “she would never want to go to a nursing home like this.”

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Facts [continued]

- The husband-father also said that she should not be placed in a nursing home, but felt "that once she gets over this that she will come back home and [resume her housekeeping duties]."
- As conversations were ongoing, Donnie reported to the team "she wants to stop the artificial feedings. She knows that she will die soon after that."

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Facts [continued]

- The attending physician was astonished. He didn't understand how the patient could have expressed this wish. Donnie told him that she communicated with him via a series of eye blinks – one blink yes, two blinks no. He had established this system with his mother over time and he said her responses were consistent.

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Facts [continued]

- The attending physician visited the patient at the bedside with Donnie, Donnie's wife, the nursing supervisor, and the patient's primary nurse. In an hour and a half "conversation," the attending physician and team came to believe that the patient had decision making capacity and that she refused tube feedings and that she would die shortly afterward as a consequence.

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Facts [continued]

- The attending physician called for a clinical ethics consultant to review the case: "I'm convinced this is what she wants. Tears welled in her eyes as we had conversation. She understands what she's doing. She's locked-in. She doesn't want to go to a nursing home."
- "What is Locked-in Syndrome?"

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Is this an ethical dilemma?

Why?

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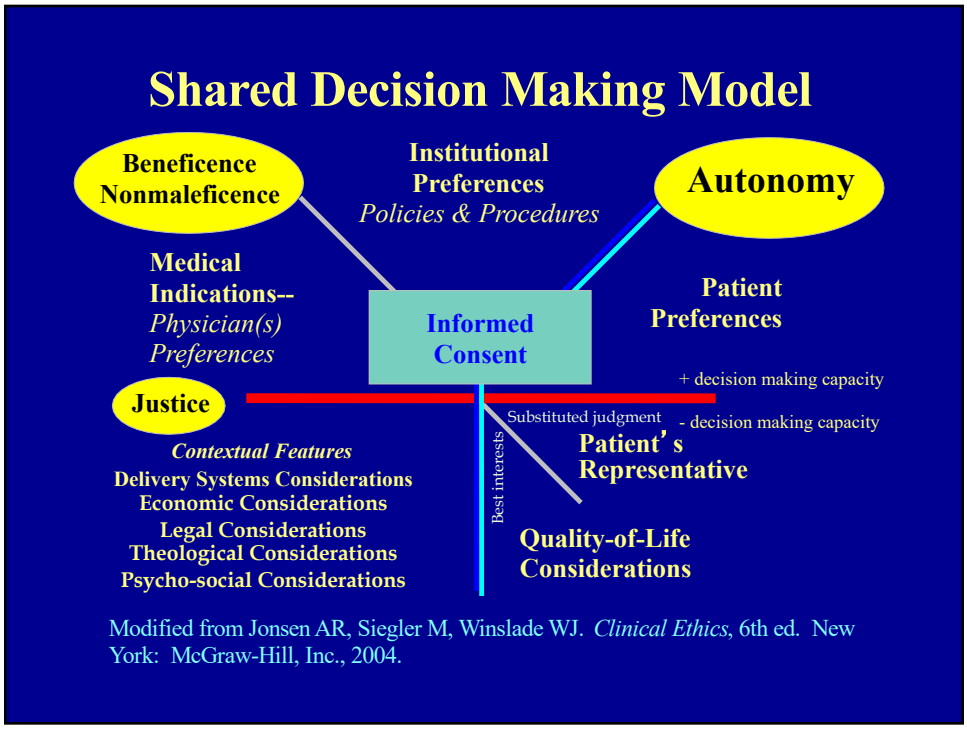

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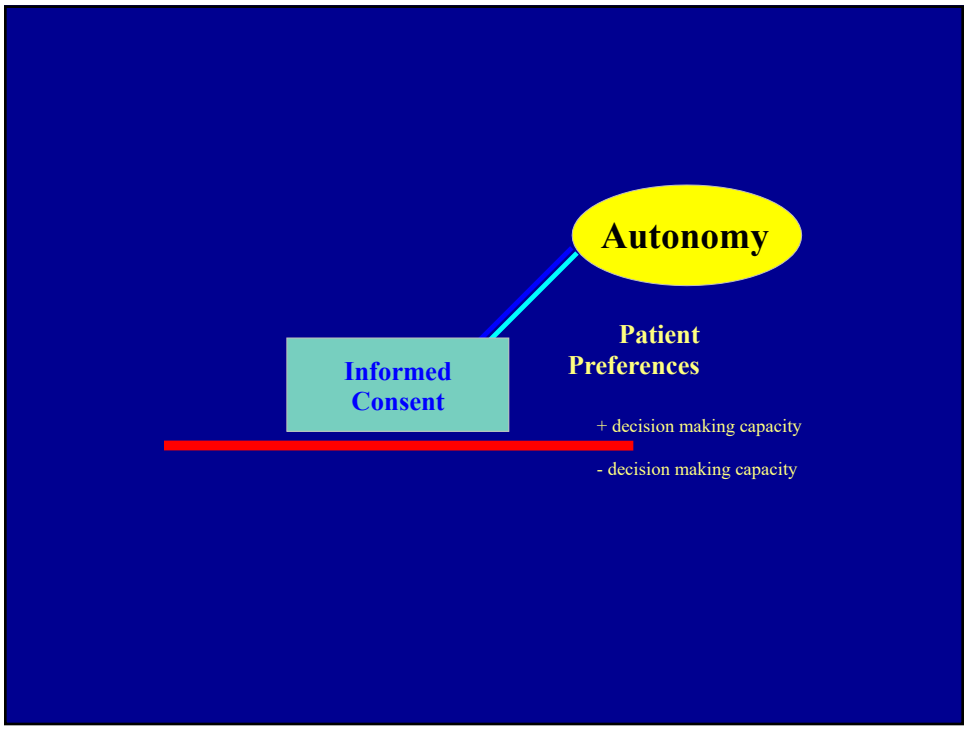
Autonomy
Patient
Preferences
Informed
Consent
+ decision making capacity
- decision making capacity

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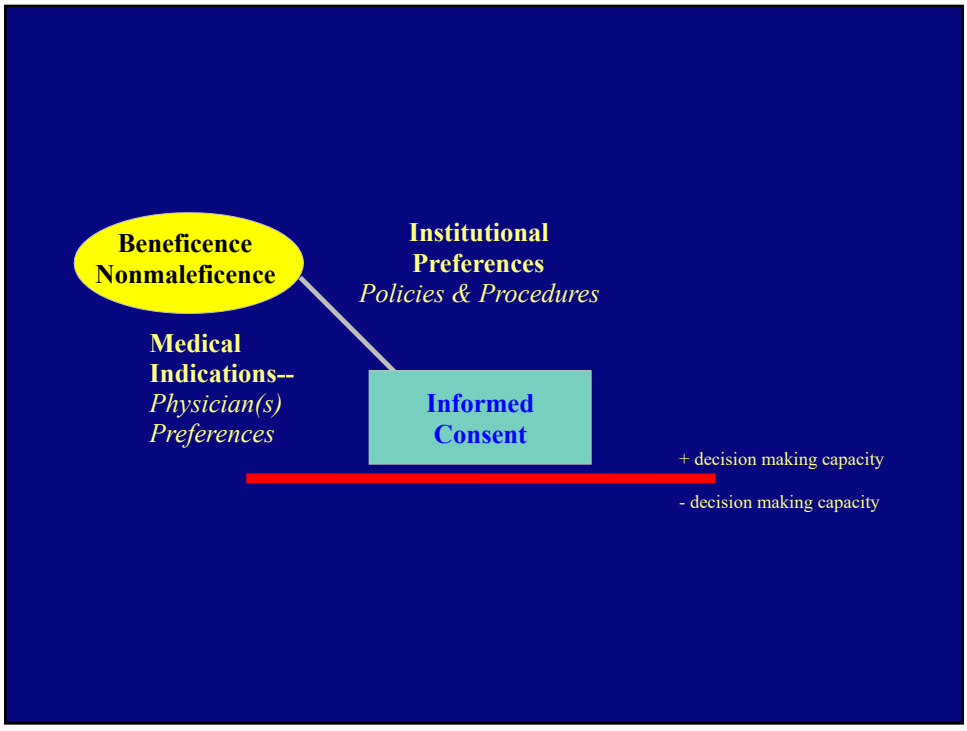
Beneficence
Nonmaleficence
Institutional
Preferences
Policies & Procedures
Medical
Indications--
Physician(s)
Preferences
Informed
Consent
+ decision making capacity
- decision making capacity

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Facts [continued]

- The clinical ethics consultant confirmed the attending physician's views in a second conversation with the patient and reviewed the ethical obligations with the team.
- The attending physician withheld feedings and instituted a comfort care plan based on his "conversations" with the patient.

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Facts [continued]

- So what happened?
- Why is this case so haunting?
- What is the rest of the story?

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