



Decision-making on Behalf of Children and Adolescents

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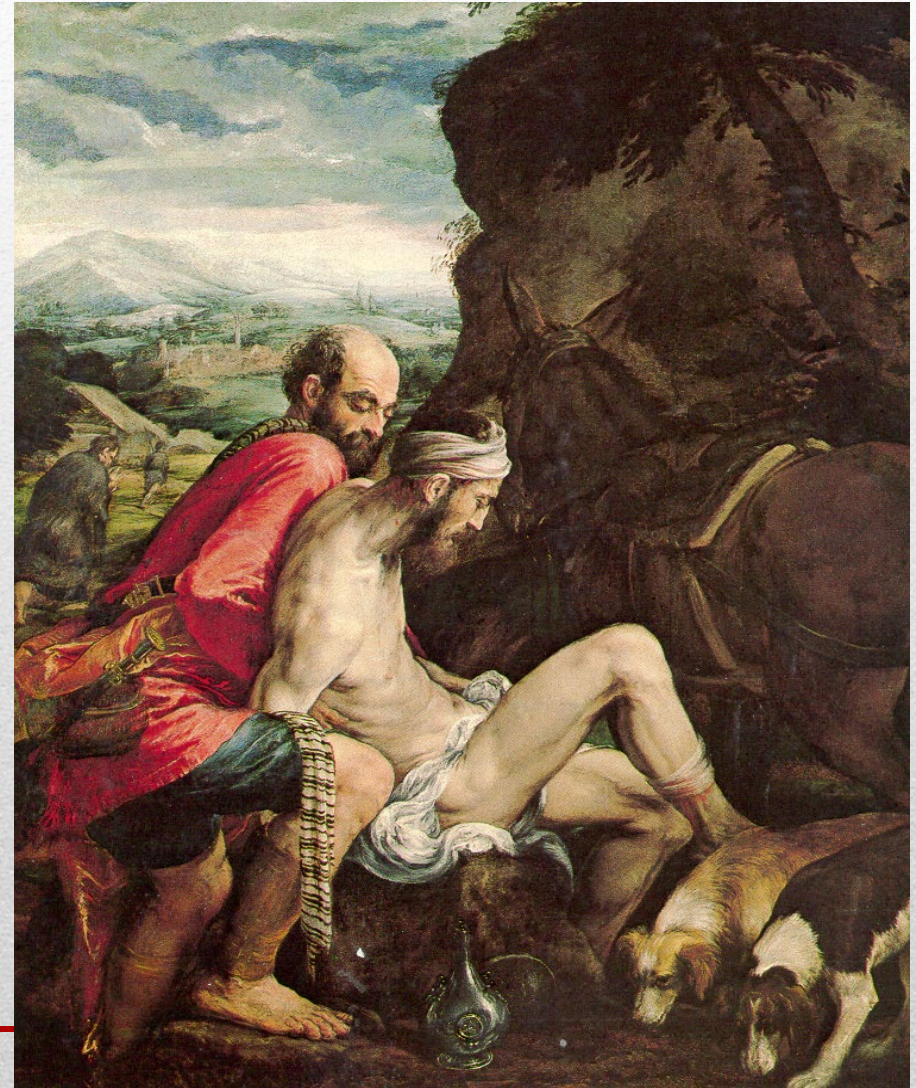
Taige

- 5 week old with fever (101.3) brought to ED
 - Physician felt Taige was irritable and lethargic—looked sick
 - Physician judgment: 3-5% risk of SBI
 - Mother refuses spinal tap, hospitalization, or treatment
 - After persuasion fails, SW and CPS called
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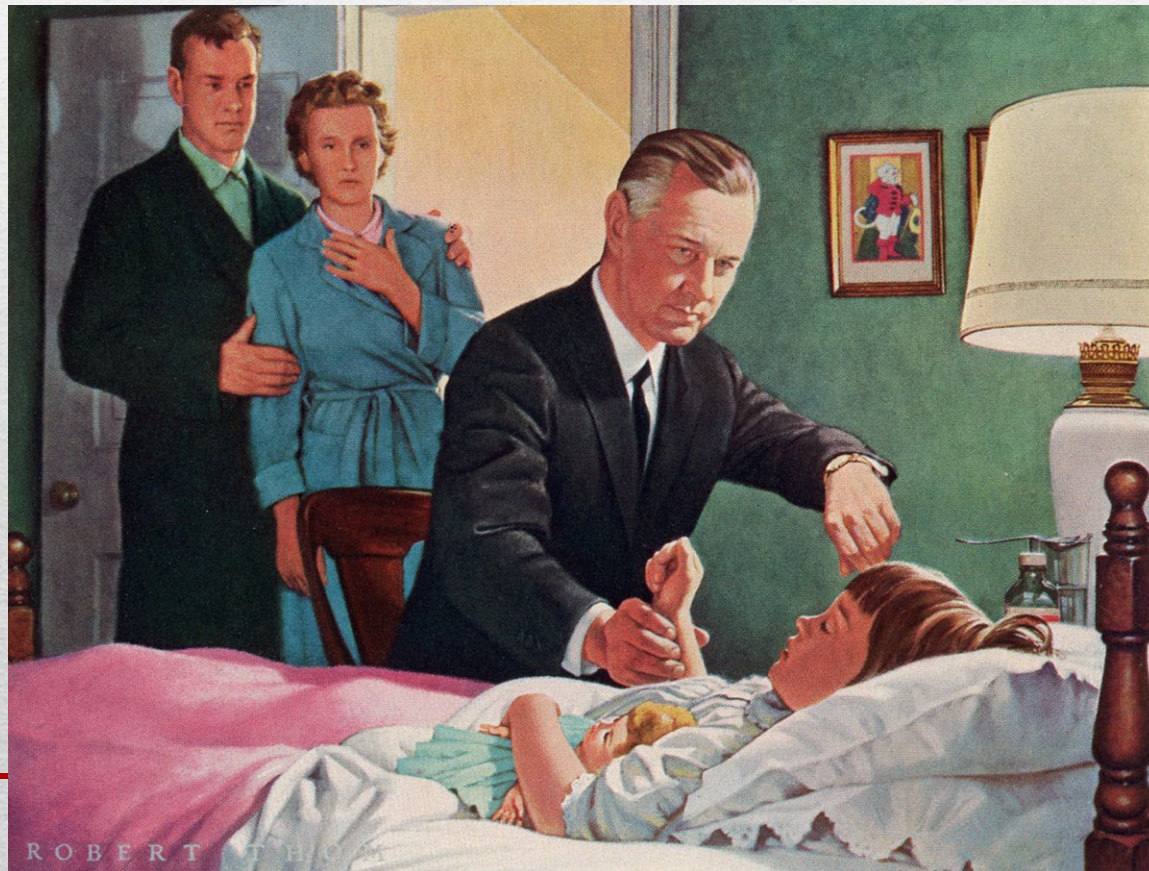
Beneficence

- “To Do Good”
- Obligation to seek the good of others
 - Avoid inflicting harm
 - Prevent harm
 - Promote good



Beneficence

Medicine is a form of applied beneficence



Beneficence

Medicine is a form of applied beneficence



....so is parenting



Parental Decision-making Authority

- Moral, social, and legal grounding
 - Parental Permission vs. Informed Consent
 - Parents expected to make decisions based upon the “best interests” of the child
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- The “democratization” of expertise, decreased trust in actual experts, social media influence, and “fake news”
- The politicization of medical matters (and vaccination)

A Sidebar on Recent Social Developments

Two Basic Disagreements

- Parents who *decline* a medical recommendation
 - Parents who *request* a medical intervention that the clinician does not feel is indicated
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Parents who Decline Recommended Rx

- HCPs cannot treat a competent adult (except in an emergency) without that person's permission
 - HCPs cannot treat a child without parental permission absent the authorization of the state
 - Communication and Persuasion are the clinician's primary tools
 - "Diagnosing" the reasons for the refusal can be helpful
 - Asking the state to intervene is the only other recourse
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State Limits on Parental Authority

- Parental Incompetence
 - Neglect or Abuse
 - Violate the Harm Principle
 - Significant Risk of Serious Harm
 - Child interests not always separable from family interests
 - Form of “Medical Neglect”
 - Sets a higher threshold than “best interests”
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The Harm Principle

“The only purpose for which power can rightfully be exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.”

--John Stuart Mill, *On Liberty*

Conditions that justify state interference

- Parent's action places the child at significant risk of harm that is serious and imminent
- Interference is necessary to prevent harm, likely to prevent harm (proven efficacy), and is not associated with similar risk of similarly serious harms (Proportionality)
- No less restrictive alternative exists that would be equally effective at preventing the harm
- Test of Generalizability
- Test of Publicity (others would agree it is reasonable)

Diekema DS. *Theoretical Medicine and Bioethics* 2004; 25(4): 243-264.

Feinberg J. *Harm to Others*. NY: Oxford U Press, 1984

Religious Objections to Care

Does it matter if the parental refusal is
culturally or religiously based?

Religious Objections to Care

“The right to practice religion freely does not include the liberty to expose the community or child to communicable disease, or the latter to ill health or death....Parents may be free to become martyrs themselves, but they are not free to make martyrs of their children.”

- Justice Holmes, *Prince v. Massachusetts*, 1944
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Religious Objections to Care

- Examples:
 - Jehovah's Witnesses
 - Christian Scientist
 - Response:
 - Understanding
 - Respect
 - Attempt accommodation
-



Parent Requests or Demands

Should be carefully considered,
treated respectfully, but need not
always be complied with

Grounds for Refusing a Request

- The likelihood of harm to the patient greatly exceeds the likelihood of benefit
 - The request falls outside of the realm of accepted medical practice
 - The request falls outside of the realm of your expertise or training (consider referral)
 - The intervention would not work (futility)
 - Cooperating with the request would harm someone else (public health threat, poor use of available resources)
 - Conscientious Objection
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Suggestions

- Consider accommodating parents when...
 - Intervention will not harm the child
 - Intervention does not significantly harm others
 - Potential for benefit is possible, but not established
 - Appropriate to limit interventions to those within the scope of the provider's practice/standard of care
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Patient Preferences & Older Kids

“Neither Youth nor Childhood is Folly or Incapacity. Some Children are Fools and So are some Old Men.”

--William Blake



Daniel Hauser

- 13-year-old
- Sleepy Eye, Minnesota
- Hodgkin's Lymphoma (90% chance of cure)
- Had one round of chemo
- Medicine Man and church Elder in Nemenhah, an American Indian religious organization



Daniel Hauser



- Claims treatment would violate his religious beliefs
 - Chemotherapy is self-destructive and poisonous
 - Wants to pursue an alternative regime of complementary medicine including dietary changes and “ionized” water.
 - “I’d fight them if I had to take it again. I’d punch them and I’d kick them.”
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Adolescents and Consent: The Legal Framework

- Conditional consent-emergencies
 - Emancipated minors (court order, marriage, active duty military)
 - Condition-specific exceptions
 - Psych, STD, Pregnancy, Drug/Alcohol
 - Mature minor
 - Generally above 15
 - Understanding of nature, purpose, and consequences of proposed treatment
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Traditional Ethics Approach

- Policy Statement on Informed Consent, Parental Permission, and Assent in Pediatric Practice, 1995
 - “There are clinical situations in which a persistent refusal of assent (ie, dissent) may be ethically binding....A patient’s reluctance or refusal to assent should also carry considerable weight when the proposed intervention is not essential to his or her welfare and/or can be deferred without substantial risk”
 - Factual Basis—Studies by Weithorn and Campbell in the early 1980s
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Children and Capacity

- Legal presumption of incompetence
 - Developmental evidence of progressive decision-making abilities, but...
 - Adolescents often do not perform at a level commensurate with their cognitive abilities
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The Adolescent Brain



Adolescent Brain Development

- Balance between the two systems:
 - “Rational”: PFC
 - “Socio-Emotional”: Limbic Structures
 - Maturation occurs “back to front”
 - PFC is not fully matured till mid 20s
 - Adolescent Imbalance: Less active pre-frontal, more active reward response system (ventral striatum) and limbic system
 - Females 2 years ahead of males
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The adolescent brain “has a well-developed accelerator but only a partly developed brake.”



Photo by Tiago Fioreze [Creative Commons license]

• --Laurence Steinberg, Psychologist

Implications: PFCDD?

- Impulsive, Inflexible
 - Aggressive, Reckless
 - Emotionally volatile
 - Risk-taking: Less sensitive to risks and more sensitive to possible rewards
 - Reactive to stress
 - Vulnerable to peer pressure
 - Respond to short term-rewards, excitement, and arousal
 - Underestimate long term consequences
 - Overlook alternatives
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Adolescent Decision-making

- **Imbalance** between development of the pre-frontal (later) and sub-cortical areas (early)
 - Very good at decision-making tasks, **but...**
 - not in emotionally charged situations or under pressure (including peer pressure)
 - Very sensitive to environmental cues, affective elements, rewards and punishments, presence of peers
 - Decisions may weigh current rewards and feelings at expense of future consequences
 - More likely to act impulsively without full consideration of consequences
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Respecting the Adolescent



- Involvement in Discussions and Decisions
 - Recognize developing capacity
 - Recognize that even at 17, their decision-making may differ from “mature” decision-making
 - Recognize the kinds of situations in which decision-making may be flawed
 - May need limits and direction
 - Physical restraint *always* requires justification
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Bottom Line

If the decision is one that we would not allow a parent to make on the adolescent's behalf (places the adolescent at significant risk of serious harm as compared to rejected alternatives), we should be very reluctant to allow the adolescent to make it.

One Final Note:

Procedural Justice is important. There needs to be a process for resolution of disagreement that is fair, transparent, and inclusive

