“Though originally intended to improve our deeds, the practice of ethics, if truth be told, has, at best, improved our speech.”

– Leon Kass, MD
“Whatever else medical ethics is, it must have something to do with the practice of clinical medicine, or at least it should.”

–Mark Siegler, MD

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The 4 Principles

1. **Autonomy**
2. **Beneficence**
3. **Non-maleficence**
4. **Justice**


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THE 4 Boxes

- **Clinical Indications**
- **Patient Preferences**
- **Quality of Life**
- **Other Factors**

Clinical Indications
- Medical facts:
  - Diagnosis
  - Etiology
  - Course of disease
  - Prognosis
  - Therapeutic options and their efficacy

Patient Preferences
  = Autonomy
  Crucial steps:
  1. Decision-Making Capacity?
  2. If yes, does the patient understand the Clinical Indications?
  3. If not: Advance Directives?
  4. If not: Who is the appropriate Surrogate Decision-maker?

THE 4 Boxes

Quality of Life

EXTERNAL, THIRD PERSON’S assessment, NOT the patient’s!

- Patient’s assessment ≠ “Patient Preference”
- Who can really judge someone else’s QOL (including patient’s future self)?
- Role of (unrecognized) bias/discrimination
- Determines Best Interests

Other Factors
(Contextual Features)

- Money, money, money
- Family considerations
- Cultural considerations
- Religious considerations
- “Good of the many vs. Good of the few, or the one.” (Individual vs. Society)
- Justice
  - Fairness
  - Disparities in healthcare treatment and outcomes

Important concepts:

1. Decision-making capacity (DMC)
2. Substituted Judgment (Autonomy): what patient WOULD have wanted (not what the surrogate wants)
3. Best Interests (Beneficence): Prolonging survival? Alleviating suffering?
4. Advance Directives (Living Will, Durable Power of Attorney for Healthcare)

Case 1

• After an uneventful pregnancy, a woman delivers a health baby boy.
• Prior to discharge from the hospital the infant undergoes newborn screening and is found to be prelingually deaf with complete sensorineural hearing loss.
• The family is referred to an audiologist who recommends a cochlear implant for the child.
• He is physically an ideal candidate and an implant would give him the best chance at spoken communication.


Case 1

Well, Not Exactly

• The parents, who are both culturally Deaf, oppose the cochlear implant.
• They view his deafness as a part of who he is rather than as a deficit or a disability requiring medical intervention.
• They desire for their son to truly share in their family's culture and communicate fluently with them in ASL, their native language.
• They worry than an implant could potentially inhibit his full participation in their community.
• They also express fears that an implant would signal to their child and society that something was wrong with him by viewing his deafness as pathological rather than an integral piece of his identity.


Case 1

Thoughtful

• When asked to further clarify their concerns, the parents state that at the very least, the decision to implant should be made by their son when he is at an age to appropriately weigh
  • the pros and cons of the procedure
  • the risks/benefits of the device
  • the resulting impact of an implant on his life.

What do you think?

How would you analyze this case using the 4 Box Model?

<table>
<thead>
<tr>
<th>Clinical Indicators</th>
<th>Patient Preferences</th>
<th>Quality of Life</th>
<th>Other Factors</th>
</tr>
</thead>
</table>

Patient Elements of Informed Consent

<table>
<thead>
<tr>
<th>Decision-making capacity</th>
<th>Voluntariness</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) understand</td>
<td>? Strong recommendation</td>
</tr>
<tr>
<td>(2) appreciate the consequences</td>
<td>Framing (“the spin”)</td>
</tr>
<tr>
<td>(3) reason about the options</td>
<td></td>
</tr>
<tr>
<td>(4) make and communicate a choice</td>
<td>“Nudge”</td>
</tr>
</tbody>
</table>

Decision-making capacity is DECISION-SPECIFIC

Framing (“the spin”)

“Nudge”

Comparison of standards for assessing patients’ capacities to make informed decisions.
Case 2

• A 4 year old male child was noted by his preschool teacher to have light and noise sensitivity.
• He demonstrates little social interaction with other children and avoids eye contact.
• He spends much time lining up objects and rarely responds when called, even for snack time.
• He is also noted to flap his arms frequently when excited.

Case 2

• The teacher brings up her concerns with the child's parents, both of whom are highly successful professionals (maybe doctors?). The parents begin arguing with the teacher, denying her observations. They become angry and storm out.

• The next day, the child returns to school, and the parents act as if nothing had happened.

Case 2

• The teacher broaches the subject again and advises an evaluation. The parents politely decline, stating, "our pediatrician mentioned the same thing 2 years ago, but we disagree."
What do you think?

How would you analyze this case using the 4 Box Model?

Beneficence
“Medical” Values
Paternalism

Free Choice
“Individual” Values
Autonomy
Thanks so much for your attention!

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Extra slides
Informed Consent Process

- "reasonable patient standard"
- "reasonable professional standard"
- "subjective standard"
  - Probable/common outcomes
  - Really bad outcomes
  - Not necessary for standard procedures involving minimal risk
  - Ongoing dialogue and exchange of information

IC = I + V

Informed consent = (proper) information + voluntariness

Double Standard?

- Informed Consent
- Informed Refusal
Rationing

- What is “cost effective” and how is it determined?
- How do we fairly (justly) allocate resources?
- Who Rations?
  - Federal vs. Local
  - Bedside rationing and the doctor-patient relationship
- On what basis?
  - “Dispassionate” medical indications
  - Good of the individual vs. good of society

What is “futility?”

Physiological futility
  Won’t work (defibrillation in PEA arrest)
Quantitative futility
  Very little chance of working (LVAD in myocardial depression from bacterial sepsis)
Qualitative futility
  Won’t produce adequate QOL (ICD in end stage Alzheimer)

Clinician Elements of Informed Consent

- Description of the procedure or intervention
- Description of any reasonable foreseeable risks or discomforts
- Description of any benefits to the patient
- Disclosure of appropriate alternative procedures or courses of treatment
- Documentation of the process of informed consent