Ethics, Morality and Cultural Competence in Decision Making

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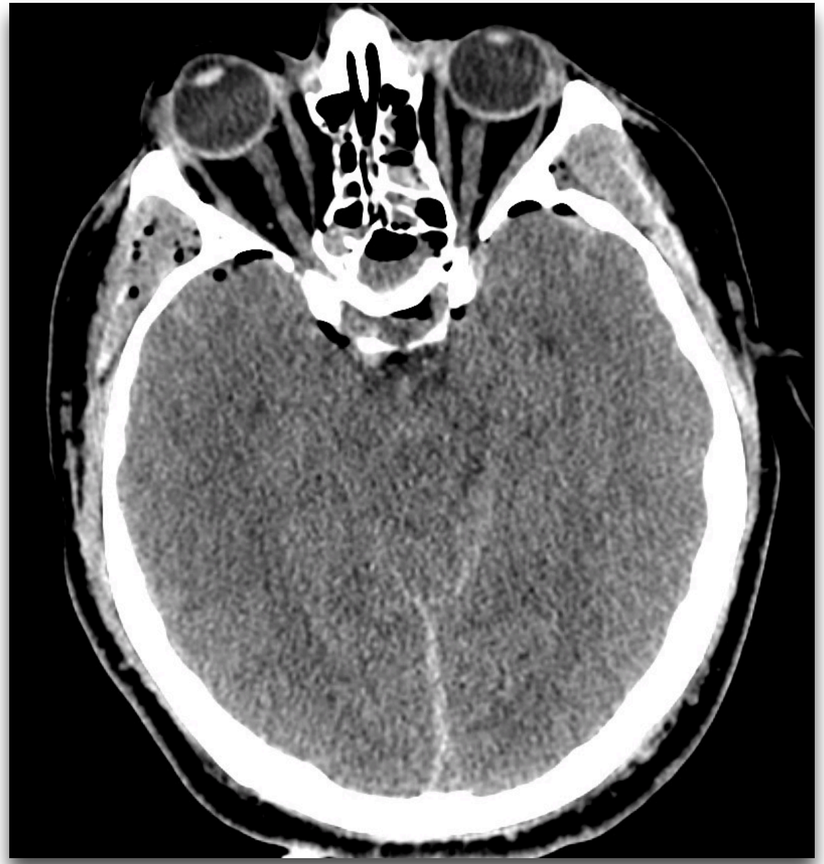
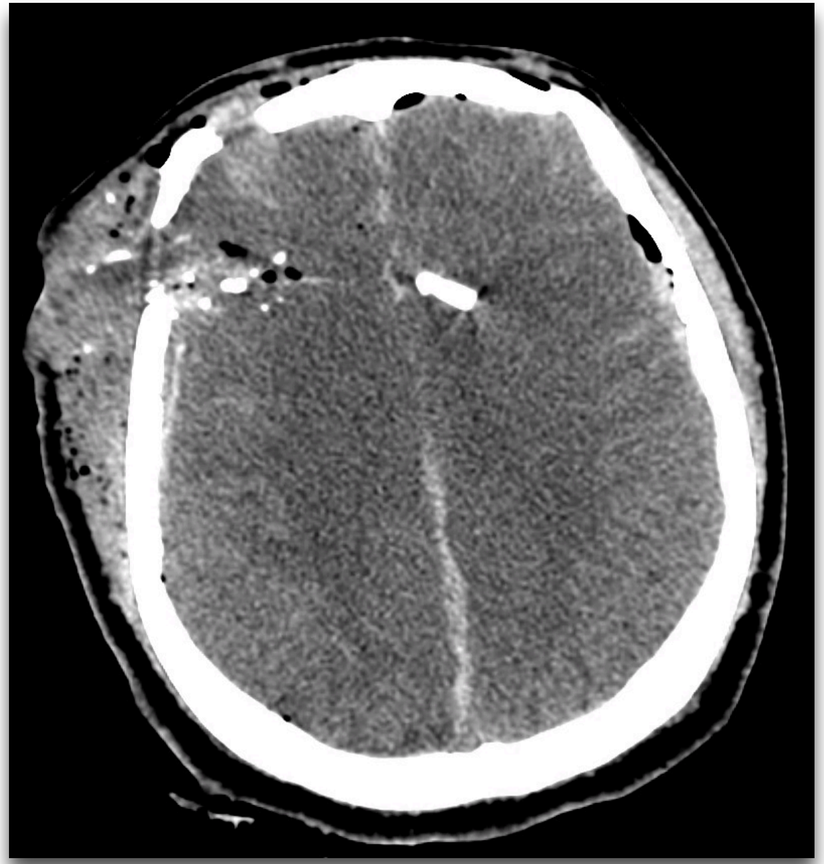
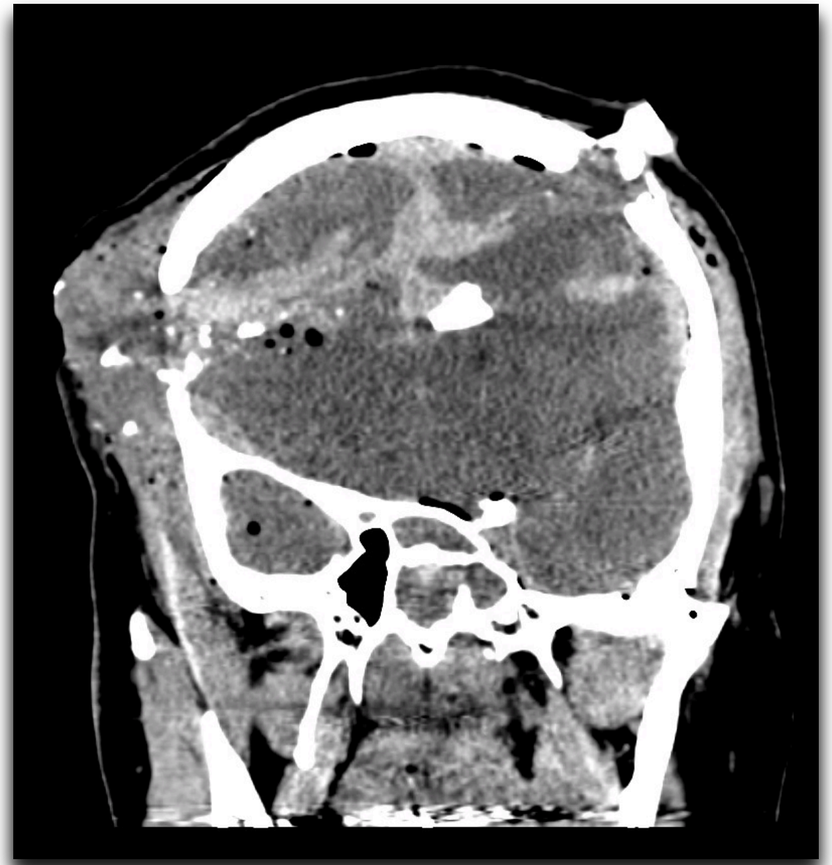
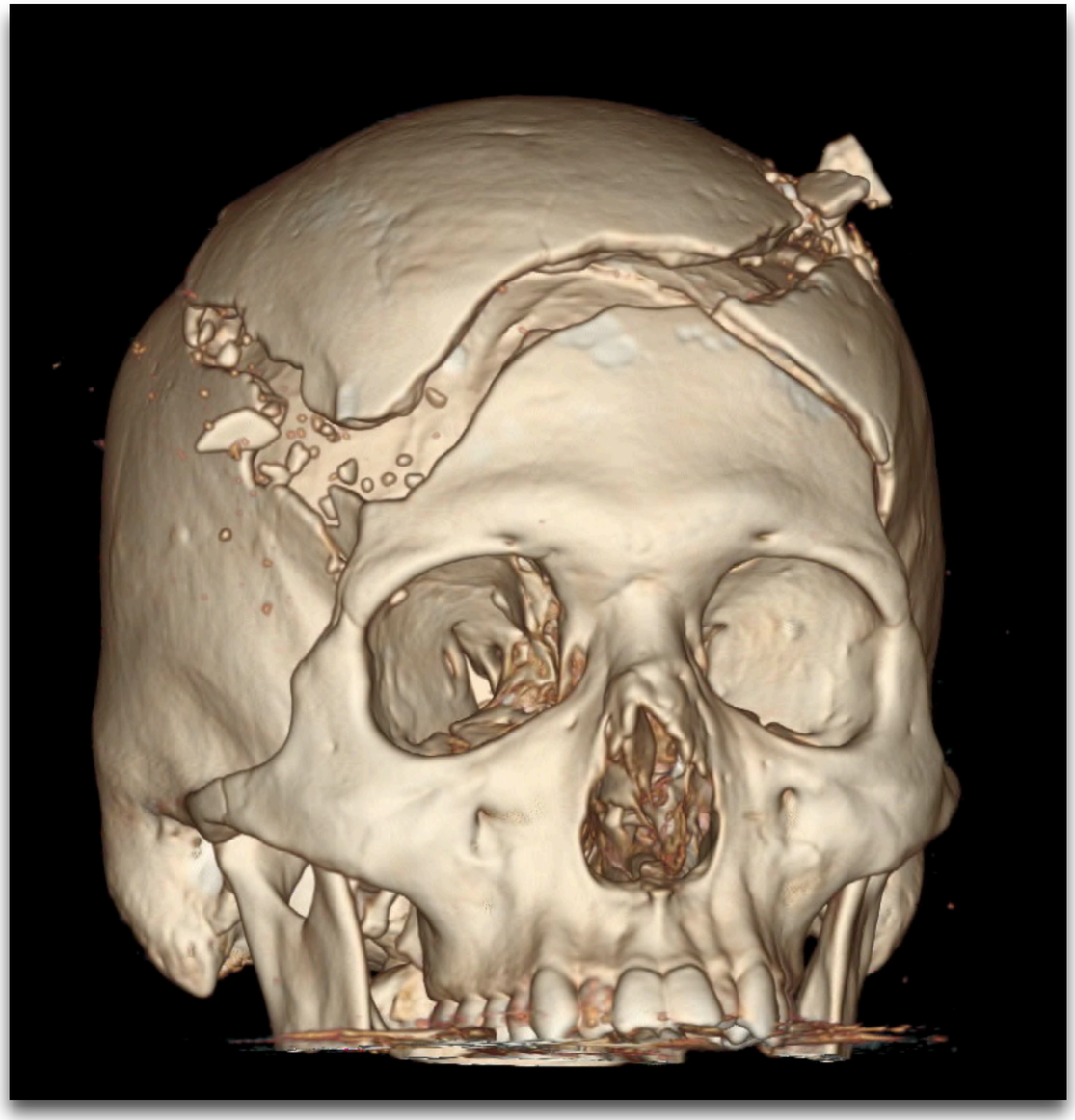
Case Presentation: HPI

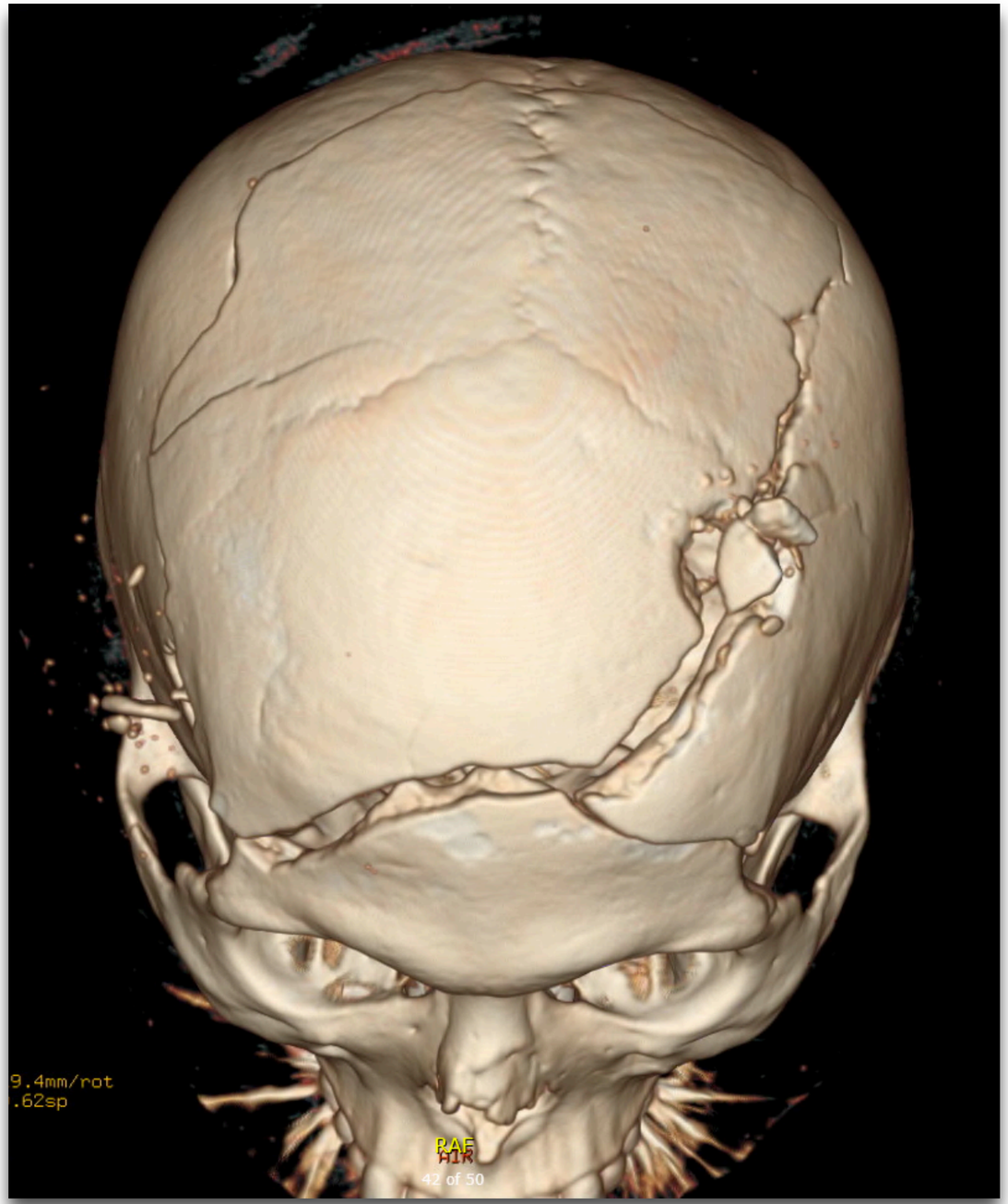
- 30 year-old man presented with GSW to head, possible self inflicted.
- GCS 3 in the field, 3 in ED, and 3 on Neurosurgery evaluation.
- BP 84/46 mmHg, HR 138
- Pupils 5 mm bilaterally, sluggish.
- Positive left corneal reflex
- Intubated and taken to CT







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Hospital Course

- Patient's penetrating TBI deemed non-survivable.
- Family informed that patient would not survive.
- Admitted to ICU without any procedures or invasive neuromonitoring.
- HD #1 - Pupils reactive, extensor posturing, GCS 3Vt. Brain matter exuding through open skull fracture. DI treated with DDAVP.

Family Meeting HD#1

- Large Hispanic family and friends, including Mother, 2 sisters and a brother.
- Family updated with patient's clinical status. They were shown the head CT.
- Family informed of overall grim prognosis.
- Family wishes to have everything done. Made DNR.

Hospital Course

- HD #1 - #3: no clinical improvement. Bedside washout of scalp wound and closure. Continue to require DDAVP for DI.

- Family updated daily regarding lack of improvement.

Family Meeting

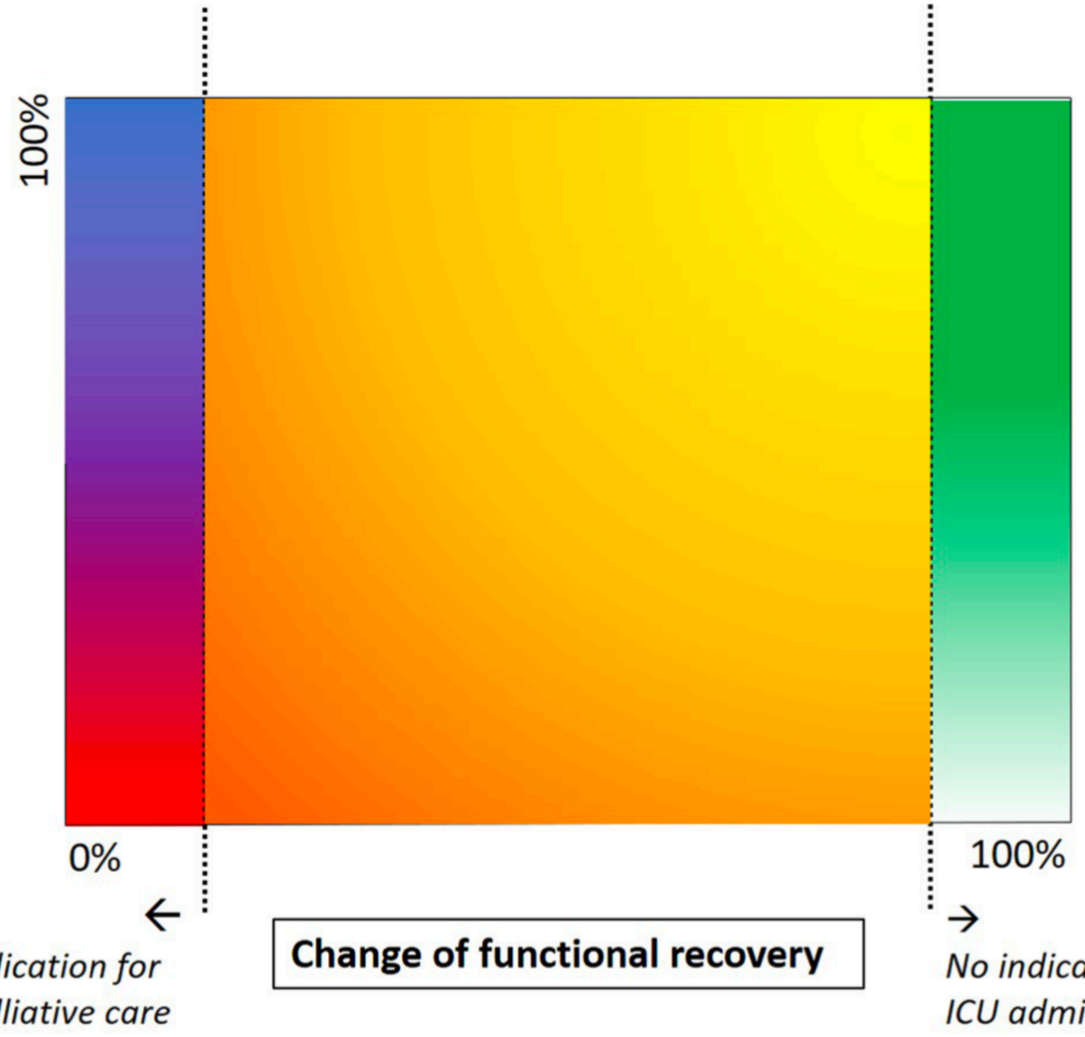
- Multidisciplinary meeting with translator, Palliative Care, nursing staff, and Chaplin.
- Family updated regarding lack of clinical improvement after 72 hours. Chance for functional recovery extremely poor. Patient would most likely require 24/7 care in nursing facility.
- Family responded that they are a close knit family and have community support and will look after the patient. They want everything done to keep his body alive, even if there's no chance of regaining cognitive function. They will leave his fate to God.
- After 2 hours of meeting, the mother said, "do the providers no longer want to care for my son?"

ICU Patients

Context of situation, i.e.:

- Required time to adapt
- A patients personal wishes
- Resiliance

(abstract scale)



Discordance

- Moral distress for providers
- Families have distrust of providers
- Patient autonomy vs. Professional autonomy

Why Does Discordance Arise?

1. Is the treatment futile or inappropriate?

2. Is it ethical to provide the treatment?

History of Futility

- Egyptian surgeons 3,000 years ago distinguished those in whom prognosis was favorable, doubtful and hopeless

- Hippocratic physicians recognized that when patients were “overmastered by the disease,” physicians should realize that medicine is powerless. Moreover, patients must not seek to be treated in such cases. Doctors, however, should study why treatment fails, try to correct the defect in medicine, and prevent harm by futile treatments.

Pellegrino, *HEC Forum.*, 2005

History of Futility

- Up until 1970's, futility had been a unilateral decision based solely in the prognostic abilities of the physician. It corresponded to "medical" or "physiological" futility

- This changed when emphasis began to be placed on the principle of autonomy - the legal and moral right of patients to refuse even life-saving treatment

- Over time, the right of autonomy, which began as a negative legal right of refusal of treatment, underwent metamorphosis to a presumptive moral right to request and demand treatment.

Pellegrino, *HEC Forum.*, 2005

Why Does Discordance Arise?

- 2 different consequences of beneficial health care:
  1. Improved physical well-being - objective medical determination
     - Lumbar discectomy removes herniated disc and decompresses the nerve.
  2. Improved overall well-being - subjective determination by patient
     - Resolution of radicular pain, return to normal activities and improved quality of life.

Taylor, *Image J Nurs Sch.*, 1995

Why Does Discordance Arise?

- 4 classification of treatments
  1. Not futile - beneficial to both physical and overall well-being
  2. Futile - not beneficial to either physical or overall well-being
  3. Futile from patient's perspective - medically indicated, not valued by patient
  4. Futile from clinician's perspective - not medically indicated, but valued by patient

Taylor, *Image J Nurs Sch.*, 1995

Assessment of Futility

- 2011 California Medical Association defined non beneficial interventions as those that “in a physician’s professional judgement, produces effects that cannot reasonably be expected to be experienced by the patient as beneficial or to accomplish that patient’s expressed and recognized medical goals, or has no realistic chance of returning the patient to a level of health that permits survival outside of the acute care setting”

- AMA - inappropriate interventions merely prolong the dying process or when the patient is in persistent vegetative state

- Inappropriate when the patient will not survive outside the acute care setting or when the patient has irreversible severe neurologic injury

Kon et al, *Crit Care Med*, 2016

Assessment of Futility

- Imprecise prognostication
  - Physicians usually overly pessimistic, especially concerning neurological recovery
- Lacks value input from patient and patient family
  - Need to separate “effectiveness” and “benefits” in order to separate objective and subjective

Assessment of Futility

- Collaborative definition of the end or purpose which an intervention is presumed to serve
  - The end or purpose must be both medical-technical and personal-value specific
  - Physicians, patients, and surrogates need to agree on ends and the possibility and probability of their being achieved by the proposed intervention
- Is some good for the patient being served by continuing treatment? If it is, are the burdens of providing that treatment in any way proportionate, or commensurate, with the perceived benefits?

Pellegrino, *HEC Forum.*, 2005

Is It Ethical To Provide the Treatments?

	Morals	vs.	Ethics
What are they?	Principles or habits with respect to right or wrong conduct. Personal compass of right and wrong		The rules of conduct recognized with respect to a particular set of actions or particular group, profession or culture
Where do they come from?	Internal - individual		External - social systems
Flexibility	Usually consistent, although can change if an individual's beliefs change.		Dependent on others for definition. They tend to be consistent within a certain context, but can vary between contexts.

Principles of Bioethics

1. Principle of respect for autonomy
   - Patient has the right to act intentionally, with understanding, without controlling influences that would mitigate against a free & voluntary act.

2. Principle of nonmaleficence
   - Healthcare providers do not intentionally create a harm or injury to the patient, either through acts of commission or omission.

3. Principle of beneficence
   - Healthcare providers have a duty to be of a benefit to the patient, as well as to take positive steps to prevent and to remove harm from the patient.

4. Principle of justice
   - The fair distribution of goods in society.

Beauchamp and Childress, *Principles of Biomedical Ethics*

Case Presentation - Hispanic Family

- Hispanic culture is characterized by familism that is qualitatively distinct from that of non-Hispanic whites.
- Familism entails the subordination of individual interests to those of the family group
- 3 features:
  - Structural - larger family size, greater presence of extended family
  - Behavioral - fulfillment of family role obligations, such as sharing of economic resources, mutual assistance and social support
  - Attitudinal - emphasis on importance of family loyalty, reciprocity and solidarity among family members

Hispanics and the Future of America, National Academies Press, 2006
http://www.nap.edu/catalog/11539.html

Assessment of Futility

- Specific end goal - to keep the patient alive and to return him to the family regardless of his cognitive recovery
- Medical interventions required - supportive care, tracheostomy, PEG
- Burdens of interventions - peri-procedural risks, side effects of treatment
- Do the benefits of the medical interventions outweigh their risks in terms achieving the specific end goal?

Hospital Course

- Patient trached and PEGed HD #7
- Discharged to LHH on HD #60.
- At time of discharge he was opening eyes, tracking, decannulated.
- Currently still residing at LHH. Awake, alert, mute, tracks examiner, moves his right side, left side hemiplegic.
- Family continues to be involved and wants to take him home but cannot meet his needs. Currently full code.

Types of Decision Making

1. Paternalistic
   - Professional autonomy overrides personal autonomy
   - Healthcare providers make the decision

2. Informed
   - Personal autonomy overrides professional autonomy
   - Healthcare providers present the options, patient makes the decision

3. Shared
   - Balanced autonomies
   - Healthcare providers and patient make the decisions together

Shared Decision Making

- Patients and providers have different, but equally valuable, perspective and roles in the medical encounter

Essential elements, ideal elements, and general qualities of SDM: emphasis in prominently cited models[a]

	President's Commission [19]	Charles et al. [4,7,8]	Coulter et al. [52,54,162]	Towle and Godolphin [27,173]	Elwyn et al. [5,6,28,65–67]
Essential elements					
Define/explain problem	X		X		X
Present options	X	X	X	X	X
Discuss pros/cons (benefits/risks/costs)		X	X	X	X
Patient values/preferences	X	X	X	X	X
Discuss patient ability/self-efficacy[b]					
Doctor knowledge/recommendations	X	X			
Check/clarify understanding		X			X
Make or explicitly defer decision		X	X	X	X
Arrange follow-up[c]				X	X
Ideal elements					
Unbiased information	X	X			X
Define roles (desire for involvement)		X	X	X	X
Present evidence		X	X	X	
Mutual agreement	X	X	X	X	X
General qualities					
Deliberation/negotiation	X	X		X	
Flexibility/individualized approach	X	X	X		X
Information exchange		X			
Involves at least two people		X		X	
Middle ground		X			
Mutual respect	X		X		
Partnership	X	X	X	X	
Patient education		X			X
Patient participation	X	X			X
Process/stages	X	X	X	X	X

Makoul and Clayman, *Patient Educ Couns.*, 2006

Summary

- Clinical heterogeneity, pluralistic values, and the constant changing nature of social consensus make clinical decisions at end-of-life challenging

- Goals and definitions of benefit must be individualized and must include both objective and subjective elements

- Shared decision making process in order to balance patient and professional autonomy