Serious Brain Injuries and ANH:
Relating medical science and medical ethics

A.S.P.E.N.

Clinical Nutrition Week

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Learning objectives

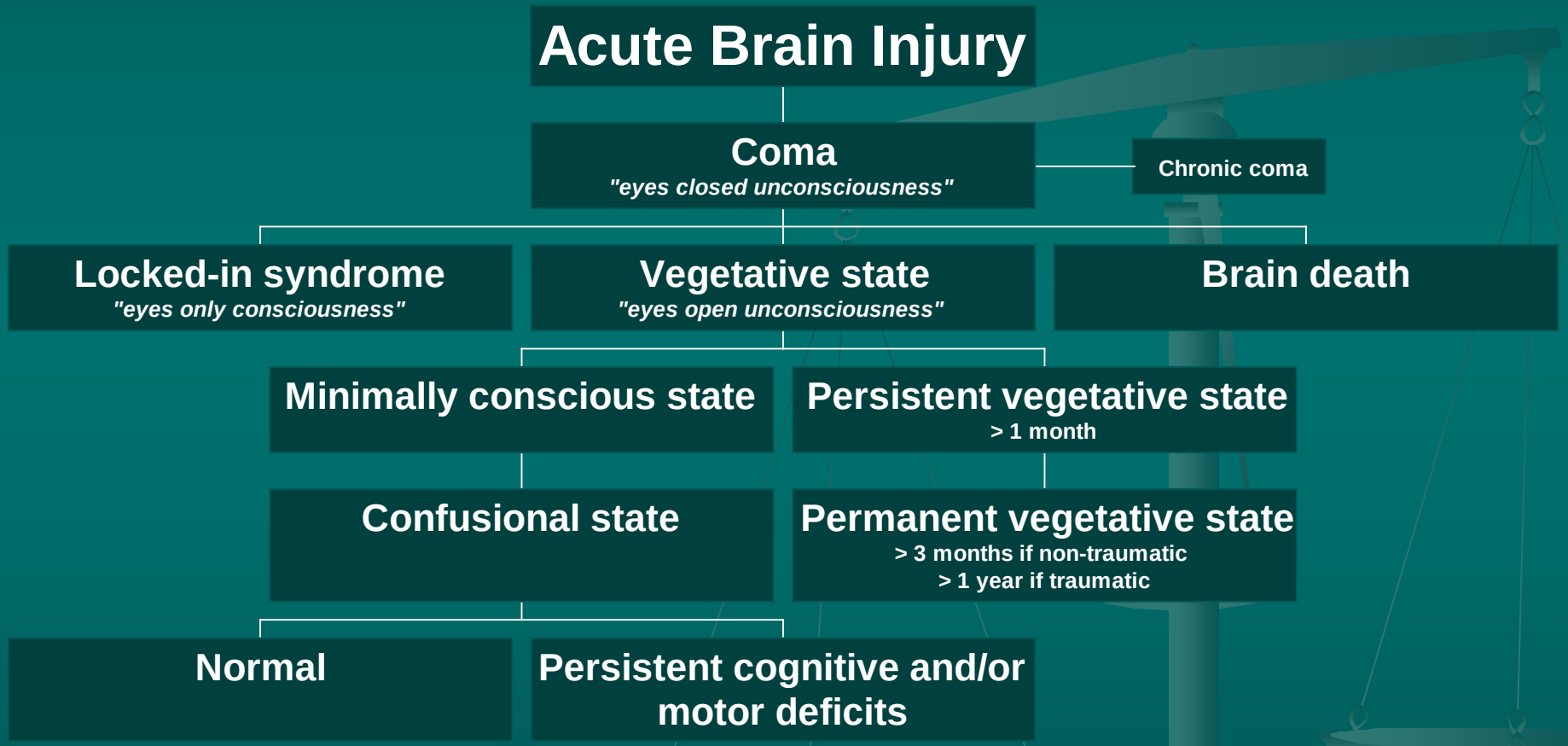
Following this lecture, attendees will be able to articulate for colleagues, patients, and families:

- The relevant clinical differences between coma, brain death, the vegetative state, and other profound brain injuries.
- The impact of ANH on suffering in serious brain injury patients and terminally ill patients.

Medical Ethics and Science

- Medical ethics is a discipline dealing with what we believe to be good or bad, right or wrong about the goals of medicine and the means used to achieve those goals.
  - *It is about what we should do, not necessarily what we can do.*
- Effective medical ethics begins with a clear understanding of good clinical medicine.
  - Much of the ethical fury in the Schiavo case was based upon misstatements concerning coma, brain death, the vegetative state,and other severe brain injuries.

Acute brain injury terminology map



Note that chronic brain diseases like dementia may lead to the functional equivalent of PVS, MCS, and persistent cognitive/motor deficits.

Coma: eyes closed unconsciousness

- Coma is the persistent absence of arousal in the face of significant stimulation. The patient appears as if asleep, but cannot be awakened. Coma is not brain death or the vegetative state.
- If recovery is to occur, it will typically begin in less than 2 - 4 weeks.
- Coma is best described to laypersons as “eyes closed unconsciousness.” It is an eyes closed unconsciousness from which the patient may or may not recover.
  - Patients rarely remain in coma forever.

Brain death

- Brain death is a product of modern technology made possible by the mechanical ventilators and CPR.
  - First suggested by two French neuropsychologists who referred to *le coma depasse* or a “state beyond coma.”
    - Mollaret, P., Goulan, M.: Le coma depasse. Rev Neurol (Par) 1959; 101:5-15
  - The need for organs to transplant led to the Harvard criteria for irreversible coma.
    - Report of the Ad Hoc Committee of the Harvard Medical School. A definition of irreversible coma. JAMA 1968 Aug 5; 205(6): 337-40
- Brain death is not coma. It is the irreversible loss of the clinical function of the whole brain, including the upper brain that we think, pray, laugh, cry and voluntarily move with; the brain stem that controls involuntary vegetative functions such as sleeping, waking and breathing; and the middle brain which links the upper and lower brain.

Brain death

- The diagnosis is a clinical judgment based upon the total absence of all brain functions.
- Cause should be reasonably established and reasonably irreversible.
  - Diagnosis may be confounded by many factors.
- Bedside testing.
  - Absent pupillary response; absent cough, gag, or corneal reflex; absent OC and VO reflex.
- Confirmatory tests
  - Technological and Apnea tests

Additional brain death testing

Plum F MD. Clinical Standards and Technological Confirmatory Tests in Diagnosing Brain Death, p. 34-66, The Definition of Death: Contemporary Controversies. Youngner, Arnold, and Shapiro. Johns Hopkins Press.1999

Test	Sensitivity (%)	Specificity (%)
EEG	+/- 90	+/- 90
Somatic evoked potentials	100	+/- 95
Brainstem auditory evoked potentials	100	94
Arteriogram	96	100
Transcranial doppler	95	99
Radionucleide perfusion scan	95	100
Apnea test	100	100

Brain death

- Brain dead, legally dead, and really dead.
- Brain death is legally dead under state law in all 50 states – no obligation to maintain treatment under the law.
- Not all cultures / persons accept whole brain death.
  - Brain dead patients may be maintained for prolonged periods with ventilatory support, pacemakers, and hormones.
    - Some who oppose withdrawal of life-sustaining treatment in the vegetative state feel the same about brain death.
    - Two states (New York and New Jersey) have a religious and/or cultural exception clause in their brain death statutes.
    - Jesse Koochin case in 2004 - brain dead child is kept alive by court order at the insistence of the parents.

Vegetative state: eyes open unconsciousness

- The Vegetative state is a product of modern technology first described in 1972.
  - Jennett B, Plum F. Persistent vegetative state after brain damage. Lancet 1972;I:734-7.
- "Eyes open unconsciousness" - a disassociation between being awake and being aware:
  - Jennet and Plum used the Oxford English Dictionary in naming this condition.
    - To vegetate is to "live merely a physical life devoid of intellectual activity or social intercourse."
    - Vegetative describes "an organic body capable of growth and development but devoid of sensation and thought."

Vegetative state: eyes open unconsciousness

- Diagnosis is a clinical judgment based upon:
  - Sleep-wake cycles but a lack of interaction with others or awareness of self when awake.
    - No visual tracking when the eyes are open.
  - No comprehension or expression of language.
  - No sustained and reproducible voluntary or purposeful response to external stimuli.
    - Spastic limbs may move non-purposively.
    - Noxious stimuli may cause reflex withdrawal.
    - Some emotive events may occur such as smiles or grimaces but not in reproducible response to stimuli.
      - Multi-Society Task Force on PVS. Statement on medical aspects of the persistent vegetative state. NEJM 1994;330:1499-1508, 1572-1579.

Vegetative state recovery

- A variety of treatments have been attempted over the years to improve the condition but none have been successful enough to become routine practice in most cases.
  - Such treatments were tried on Ms. Schiavo in 1990-1991 including thalamic stimulator implant.
  - Hyperbaric oxygen and vasodilator therapy were suggested by 2 doctors in favor of treating Ms. Schiavo. Neither could produce a single patient or study from the peer reviewed literature.
- When recovery occurs, it is usually only to a state of severe ongoing brain injury.
  - The longer one is vegetative - the worse the prognosis for meaningful neurological recovery.

Vegetative state survival

- Younger patients in particular may survive for decades if provided with Artificial (assisted) Nutrition and Hydration (ANH).
- Although patients may be cared for at home, most often they are placed in a nursing home setting.
  - Medicaid becomes the payer and they don't pay well, thus poor quality treatment ensues in many cases.
  - Diffuse contractures and skin breakdown are common.
- If ANH is not withdrawn, patients often eventually die from infections.

Post-trauma vegetative state outcome

Data from Multi-Society Task Force on PVS

	% Dead 1 year later	% Vegetative 1 year later	% Conscious 1 year later
Vegetative at 1 month	28%	18%	54%
Vegetative at 3 months	31%	30%	39%
Vegetative at 6 months	28%	53%	19%

Note bene: consciousness ≠ normal

Non-trauma vegetative state outcome

Data from Multi-Society Task Force on PVS

	% Dead 1 year later	% Vegetative 1 year later	% Conscious 1 year later
Vegetative at 1 month	47%	39%	14%
Vegetative at 3 months	36%	58%	6%
Vegetative at 6 months	18%	81%	1%

Note bene: consciousness ≠ normal

Locked - in and Minimally Conscious State

- "Locked - in" State – "eyes only consciousness"
  - Consciousness is preserved but the patient is paralyzed except for eye movement and blinking.
    - The Diving Bell and the Butterfly: A Memoir of Life in Death, by Jean-Dominique Bauby, b. 1952, "locked in" 12/8/95, died 3/9/97.
- Minimally Conscious State (MCS)
  - Sleep-wake cycles exist.
  - Arousal level ranges from obtunded to normal.
  - Reproducible but inconsistent evidence of perception, communication ability, or purposeful motor activity
  - Visual tracking often intact.
  - Communication ranges from none to unreliable with inconsistent yes/no responses, verbalization, and gesture.
    - Giacino JT, Zasler ND, Katz DI et al. Development of practice guidelines for assessment and management of the vegetative and minimally conscious states. J Head Trauma Rehab, 1997; 12: 79-89.

Anatomic injury vs. functional status seen at the bedside

	Anatomic injury		*Functional status families see at the bedside*				
	Upper Brain	Brainstem	Sleep / wake cycle	Eyes	Body movement	Gag / Breathing	Ability to suffer
Brain Death	–	–	–	Closed	–	–	No
Unconscious "eyes closed" Coma	–	±	–	Closed	–	± Usually -	No
Unconscious "eyes open" Vegetative State	–	+	+	Closed / Open *Roaming*	Reflex	+	No
Minimally Conscious State	±	+	+	Closed / Open *Tracking*	None to Purposeful	+	Yes
Focal Brain Injury and Dementia	±	+	+	Closed / Open *Tracking*	Variable Purposeful	+	Yes

Do brain injured patients suffer?

- Suffering is a first person subjective experience.
- Suffering may have physical, emotional, social, and/or spiritual components.
- Suffering is ethically relevant and the relief of suffering is perhaps the highest goal of medicine.
- Outside of the metaphysical construct of radical skepticism, consciousness appears to be a prerequisite for suffering.
- Clinical exams show the absence of voluntary or purposeful response to unpleasant or painful stimuli in brain dead, comatose and vegetative patients, but not locked in or minimally conscious patients.

Do brain injured patients suffer?

- PET scans demonstrate complete absence of neuronal function in brain dead patients and reduced cerebral metabolism in comatose and vegetative patients similar to the reductions seen in general anesthesia.
  - Laureys S, Owen A, Schiff ND. Brain function in coma, vegetative state, and related disorders. Lancet Neurology, 2004; 3(9): 537-546.

Do brain injured patients suffer?

- PET scans of vegetative patients given a painful noxious stimulus demonstrate activation of subcortical and primary somatosensory cortex but not the higher associative cortices activated in normal persons who consciously perceive pain when given the same noxious stimulus.
  - Laureys S, Faymonville ME, et al. Cortical processing of noxious somatosensory stimuli in the persisten vegetative state. NeuroImage, 2002; 17: 732-741.
- fMRI study of patients under general anesthesia also demonstrate absence of higher cortical but not subcortical brain function.
  - Antognini JF, Buonocore MH, et al. Isoflurane anesthesia blunts cerebral responses to noxious and innocuous stimuli: a fMRI study. Life Sci, 1997; 61: 349-354.

Do brain injured patients suffer?

- Solid neuroscience supports the clinical observation that comatose, brain dead and vegetative patients do not suffer.
  - Such patients experience neither burdens or benefits of any therapy.
    - The experience of “starvation” requires consciousness.
- Families and health care professionals however may feel that they are benefiting the patient with ANH.
  - Remember the symbolic and religious value of “food.”
  - Family and professional feel they are not abandoning the patient.
  - Family and professional feel they are “doing something.”
    - However, family cannot achieve closure.

Do brain injured patients suffer?

- Minimally conscious, locked in, demented and other brain injured patients in which at least some consciousness is preserved can suffer.
- This distinction is ethically relevant!
- For these patients, we must ask if ANH promotes or relieves suffering.

Does ANH Promote or Relieve Suffering?

- Multiple studies have consistently failed to show meaningful clinical benefit in terminal patients.
  - Winter, SM. Terminal Nutrition: Framing the Debate for Withdrawal of Nutritional Support in Terminally Ill Patients. *American Journal of Medicine* 109:723-726, 2000.
- ANH does not cure or reverse any organ failure disease.
- ANH does not cure or reverse any neuro-degenerative disease such (ALS, MS, Parkinson's).
- In advanced dementia patients, ANH has not been shown to promote healing of pressure ulcers or lower the risk of aspiration pneumonia. In demented patients, it has not been shown to increase patient comfort, functional status or survival compared to hand feeding.
  - Finucane TE, Christmas D, and Travis K. Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence. *JAMA, 282:14. 1365-1370*

Does ANH Promote or Relieve Suffering?

- ANH and IV hydration in dying patients are associated with increased nausea, emesis, bronchial secretions, urinary frequency, bladder distention, pulmonary edema, peripheral edema and thus the need for more intervention with catheters, other treatments, and medications.
  - Rouseau, How fluid Deprivation Affects the Terminally Ill, *RN*: 54 (1), 73-76
- A review of 5266 nursing home residents with chewing and swallowing problems not only failed to show a benefit from feeding tube placement, but revealed a significant increase in 1-year mortality among tube fed patients.
  - Mitchell SL, Kiely DK, Lipsitz LA. Does Artificial Enteral Nutrition Prolong the Survival of Institutionalized elders with Chewing and Swallowing Problems? *J Gerontology*. 1998; 53A: M1-M7

Does ANH Promote or Relieve Suffering?

- There is a wisdom to the body as we die that has been with us from the very beginning - the “Biblical death” and the quiet death of our ancestors.
  - Osler’s study of dying at Johns Hopkins: “Their death was like their birth ... a sleep and a forgetting.”
- It is natural to not feel hungry or even thirsty in most cases of serious illness and even more so in terminal illness.
- ANH prevents the very natural ketosis and dehydration that can ease so many of the symptoms associated with dying.

Does ANH Promote or Relieve Suffering?

- Fasting is associated with ketosis
  - Ketones have anesthetic properties
  - Some experts believe that fasting increases endorphin release
    - Prinz. Terminal Dehydration, A Compassionate Treatment. *Archives of Internal Medicine*, 152:697, 1992
- Patients who fast for religious or political purposes rarely complain of hunger after a rather short time
- Dehydration is associated with hyperosmolarity, azotemia, hypernatremia, and hypercalcemia
  - These events are associated with sedation and eventually coma
  - How do you want to die when your time comes?

Does ANH Promote or Relieve Suffering?

Study of 32 patients admitted to a hospice:

- 20/32 hospice patients never hungry
- 11/32 hospice patients hungry initially
- 1/32 hospice patients hungry until death
- 11/32 never thirsty
- 9/32 thirsty only initially
- 12/32 with at least some thirst on the day of death, however of those who were thirsty, it was managed with mouth moisture
  - McCann, *JAMA*, 272:1263-1269, 1994

Does ANH Promote or Relieve Suffering?

- In the most comprehensive study dealing with this issue to date, nurses of terminally ill patients who had refused food and fluids were asked to rate the patient's comfort and peacefulness through the dying process. The rating scale ranged from 0 (a very bad death) to 9 (a very good death). The median score for these terminally ill patients who chose to "die naturally" without ANH or other life sustaining technologies was 8.
  - Ganzini L, Goy ER, Miller LL, et. al. Nurses' Experience with Hospice Patients Who Refuse Food and Fluids to Hasten Death. NEJM, 349:4. 359-365.
- Our experience at Baylor is that the vast majority of dying patients when asked deny both hunger or thirst
- Hunger is easily managed with small amounts of "comfort" foods
  - The Hagen-Daz diet
- Thirst is easily managed with ice chips, sips of water or favorite liquids, and good oral care
  - Nothing wrong with a little alcohol if the patient wants it