Palliative Care and Ethics in the Neuroscience Patient

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- No off-label Rx to be discussed
- “Knowledge belongs to humanity,” Pasteur
Learning Objectives:

- Understand palliative care consultation in the management of neuroscience patients
- Understand the role of the medical ethics committee in decision-making and conflict resolution in the care of neuroscience patients
- Implement palliative care or ethics consultations when medically appropriate
Outline

- Definitions
- Palliative Care Diagnoses in Neuroscience
- Decisions for supportive interventions
- Hospice Medicare Benefit for Neuroscience Diagnoses
- Principles of Medical Ethics Decision Making
- Advanced Care Planning
- Goals of Care
- Structured Family Meetings
- Treatment Futility Discussions
- Complex situations/withdrawal of care
Definition of Palliative Care

- Treatment directed to prevent, relieve or reduce **Symptoms** of a disease without effecting a cure
- Offered throughout the spectrum of illness, including at the end of life
- Includes both medical and psychosocial treatment
- Not intended to replace disease-modifying therapy, but to augment the comfort and support of individuals and families who are living with serious or life-limiting illness

(Center for Palliative Care Education)
Definition of Ethics

“Ethics is a branch of philosophy; the formal, rational, systematic examination of the rightness and wrongness of human actions” (Pellegrino, *American Journal of Bioethics, 2006*)

Clinical Ethical Issues

- Risks, harms, burdens of disease
- Risks, harms, burdens of treatment
- Expected/Potential benefits of treatment
- Physician Perspective/Patient Perspective
- Mutually agreeable “goals” of therapy
Definition of Hospice

- Varied Definitions
  - A place to die
  - A philosophy of support with an interdisciplinary team model for end-of-life care
  - The Hospice Medicare Benefit, 1982 with refinements, based on prognoses no longer under active disease-modifying therapy where the expected prognosis to death is six months or less under usual circumstances
Consultation Triage

All hospice care is palliative care
Not all palliative care is hospice care (can and should begin far upstream from Hospice Medicare Benefit, may occasionally prolong survival/prognosis)
Palliative Care and Hospice Care both provide global symptom management (i.e., hands-on medical interventions by IDT clinicians)
Ethics consultations focus on the decision-making process and structure (double effect, informed consent, surrogacy or substituted decision making, resuscitation, futility, end-of life conscious sedation) which inform the conduct of care
Palliative Care Diagnoses in Neuroscience

- In 2010, Hospice Diagnoses included 35.6% cancer and 64.4% NON cancer.
- Of non cancer diagnoses, the following neuroscience diagnoses were present in:
  - Dementia 13.0%
  - Stroke/Coma 4.2%
  - Non-ALS NM 1.2%
  - ALS 0.4%
  - Gen Debility 13.3% (partial, includes Parkinson’s)
- Approximately 25% of all Hospice admission diagnoses were neuroscience related (the only greater non cancer was heart at 14.3%, lung is third at 8.3%)
Stroke Hospice Admission Criteria
(The National Hospice Organization, 1996)

- Acute:
  - Coma or persistent vegetative state beyond 3 days
  - In post-anoxic stroke, coma or severe obtundation accompanied by severe myoclonus lasting beyond 3 days past the anoxic event
  - Comatose patients with any 4 of the following on day 3 of coma (97% mortality within 3 months)
    - Abnormal brain stem response
    - Absent verbal response
    - Absent verbal response to pain
    - Serum Creatinine greater than 1.5
    - Age greater than 70
  - Dysphagia severe enough to prevent the patient from receiving food and fluids necessary to sustain life, in a patient who declines, or is not a candidate for, artificial nutrition and hydration
  - Specific imaging findings (CT/MRI)
Stroke Hospice Admission Criteria
(The National Hospice Organization, 1996)

- Chronic:
  - Age greater than 70
  - Poor functional status, KPS under 50%
  - Post Stroke Dementia as evidenced by a FAST Score of greater than 7
  - Poor nutritional status, whether on artificial nutrition or not
    - Unintentional weight loss greater than 10%
    - Albumin under 2.5%
  - Medical Complications:
    - Aspiration Pneumonia
    - Pyelonephritis
    - Sepsis
    - Refractory Stage 3-4 decubitus ulcers
    - Fever recurrent after antibiotics
Newer Stroke Admission Criteria
(Downing et al, *JPC*, 2007)

- PPS less than/equal to 40
  - Mainly in bed
  - Unable to perform most ADLs
  - Extensive Disease
  - Self Care mainly with assistance
  - Normal or reduced intake
  - Full consciousness or drowsy w/wo confusion
  - AVERAGE SURVIVAL PPS 30-50 IS 41 DAYS

- Inability to maintain hydration/caloric intake and one of the following:
  - Weight loss greater than 10% prior 6 months or 7.5% prior 3 months, serum albumin under 2.5.
  - History of pulmonary aspiration
  - Calorie count showing inadequate calorie/fluid intake
Newer Coma Admission Criteria
(Downing et al, *JPC*, 2007)

Three of the following on day 3 of coma:
- Abnormal brain stem response
- Absent verbal response
- Absent withdrawal response to pain
- Serum creatinine over 1.5
Amyotrophic Lateral Sclerosis

- Progressive Neurodegenerative disease of lower and upper motor neurons
- Estimated 1/3 of patients with ALS have mild cognitive impairment
- Pt may die of ALS before developing frontotemporal dementia
- Anxiety and Depression Common
- Medication (Riluzole) available—no survival benefit in 2 studies, delayed time to tracheostomy in each by several months
- Most frequent cause of death respiratory failure (some hospices accept on biPAP or CPAP
- Usual life expectancy 3-5 years
- Dysphagia commonly precedes respiratory compromise by long intervals. Placing PEG of palliative benefit, particularly so if early.
Hospice Admission Criteria for ALS (Must meet 1 of sets 1, 2 or 3)

1. Critically impaired breathing capacity as shown by all of the following:
   - VC under 30%
   - Significant dyspnea at rest
   - Supplemental O2 at rest
   - Declines artificial ventilation

2. Must have both 2a and 2b:
   - 2a. Rapid progression of ALS as shown by
     - Wheelchair bound
     - Barely intelligible or unintelligible speech
     - Pureed diet
     - Assist in ALL ADLs
   - 2b. Nutritional Impairment
     - Oral intake insufficient to sustain life
     - Continuing weight loss
     - Dehydration or hypovolemia
     - Absence of artificial feeding methods

3. Must demonstrate both 3a and 3b:
   - 3a: Rapid progression of ALS
   - 3b: Life threatening complications in prior 12 months
     - Recurrent aspiration pneumonia
     - Upper UTI, pyelonephritis
     - Sepsis
     - Recurrent fever after antibiotic therapy
Other Neurodegenerative Disorders

- Parkinson’s Disease
- Progressive Supranuclear Palsy/Corticobasal ganglionic degeneration
- Multiple sclerosis
- Multiple System Atrophy
- Common features:
  - In late stages patients are bed-bound and non-verbal
  - Death from complications such as infection and inability to sustain adequate nutrition
  - All appropriate for pre hospice palliative care
  - Establish patients goals of care while they are still able to communicate
  - Cognition variably affected except in PSP and CBGD where impaired executive function supervenes associated with emotional lability
  - Sialorrhea (Also in ALS) common palliative symptom
  - Anticholinergics important but may have double effect, particularly in Parkinson’s disease!
Hospice Admission Criteria for Neurodegenerative Diseases

- No specific NHO guidelines
- Patients are admitted under general debility diagnosis (important for attending physician and hospice medical director as GD ICD-9 code is flagged for CMS concurrent review)
- Prognostication very important, particularly in recertification after first 90 days (functional and nutritional decline documentation essential)
- Secondary problems (previously called comorbidities)—decubitus ulcers, aspiration, infections—important to accurate prognostication
Supportive Interventions in Neuroscience

- Artificial nutrition/feeding tubes
  - Feeding tube does **not** improve prognosis for patients with a primary dementia
    - Double effects of aspiration pneumonia (20%+) may actually shorten life span
    - In patients with end stage dementia, artificial feeding does not improve decubitus ulcers or skin problems
  - Feeding tube may be appropriate for ALS patients after full discussion
    - If considered, place early as definite delay in loss of VC and pulmonary function with improved prognosis occurs
  - Feeding tube may be selectively appropriate for patients with ND, especially Parkinson’s disease
    - Before buccal and transdermal medications, was generally indicated to preserve motor function and comfort from reduced tremor and spasm
    - May still be used for po route meds and to preserve body mass if ADLs and support system are permissive
  - Feeding tube is highly individualized in stroke and coma patients
  - Time limited trial of artificial feeding with/without IV fluids per NG tube is reasonable in acute stroke patients especially if not poor prognosis; does **not** improve risk of decubitus ulcers, pneumonia or urinary tract infections
Definitions of Anoxic Brain Injury

- Mild disability—good recovery
- Moderate disability—independent with ADL
- Severe disability—dependent for ADL
- Persistent Vegetative State—unawareness but awake at times
- Persistent Coma—unawareness at all times, potentially reversible
- Brain Death—unawareness at all times, irreversible
Differential Diagnosis for Brain Death

Differentiate from:
- Locked in syndrome (focal injury to pons)
- Hypothermia
- Drug intoxication
- Guillain-Barre Syndrome

Causes of Brain Death
- Hypoxic/ischemic Brain Insult
- Fulminate hepatic failure
- Severe Head Injury
- Subarachnoid Hemorrhage
Confirmation of Brain Death

- **History**
  - Documentation of cause and irreversibility
  - Absence of drug intoxication/poisoning
  - Absence of metabolic causes
  - Absence of hypothermia (under 32 degrees)

- **Physical**
  - Coma or unresponsiveness to pain stimuli
  - Absence of motor response to painful stimulus
  - Absence of brain stem reflexes (pupillary 4-8 mm, corneal, gag, cough, doll’s eyes, calorics)
  - Apnea testing (O2, CO2) HPM criteria

- **Imaging**
  - TC99m perfusion brain scan (most sensitive test)
  - Cerebral angiogram (no filling)
  - EEG (no activity 30 minutes)
  - Transcranial doppler US

**APNEA TEST CONFIRMATORY: IMAGING IF IT CANNOT BE PERFORMED**

- Document History and Physical Before above testing
- Brain death determination official time of death by WV statute
Terminal Extubation

- Required for Brain Death after Confirmation
- Selectively applied for treatment withdrawal after time-limited trial
- Goals to prevent dyspnea and distress
- Opioids and benzodiazepines important, titrating actively to comfort
- All alarms should be off
-Ascertain that all questions have been resolved; consider ethics consultation if goals of care remain unclear
- Actively involve all support systems; in most cases IN ADVANCE of terminal extubation (palliative care and spiritual care especially)
- Best to conduct in late morning or early afternoon hours
- Median survival 35 minutes to 7.5 hours (2 minutes to 9 days)
- If survival over 8 hours, transfer to a palliative bed setting
Medicare Hospice Benefit for Neuroscience Patients

- Hospice is a Medicare Part A Benefit
- Hospice Medicare Benefit covers 100% (normally 80-20 on Medicare) of cost for services related to Hospice diagnosis
- Patients are still covered by Part A at 80-20 for services unrelated to the Hospice diagnosis
- Eligibility for benefit:
  - Eligibility for Medicare A
  - Certified as terminal with a life expectancy of 6 months or less if “disease runs its usual course” (a terminal diagnosis must be provided)
  - Certification must be by both the primary attending physician and the hospice medical director. A Physician Narrative as of 2012 is now required. The physician must sign a statement of attestation that he/she personally composed the narrative.
  - Only a medical doctor or doctor of osteopathy can certify or recertify a terminal illness (AHP not permitted to do so)
- Once on Hospice all services related to the Hospice terminal diagnosis must be paid by the Hospice (increased oversight in 2011-2012)
  - This has most effect in oncology settings, with less for neuroscience
- Recertification is required at 90 or 60 day intervals with Physician Narrative. Within 2 weeks of 180 days and every 60 thereafter a Face to Face Visit with Narrative is required. Although ANP can conduct the exam, the physician still must attest to personal preparation and submission of the narrative and additionally attest that it was completed.
- Caveat: Beginning in 2011 CMS reviewers have focused reviews on diagnoses that may extend in excess of 180 days, with special attention to patients with DEMENTIA diagnoses.
Levels of Hospice Care

- **Home care**
  - Home, relative’s home, assisted living and domiciliary facilities
  - Appropriate for dementia, ALS, chronic stroke, neurodegenerative diseases such as Parkinson’s where trajectory of decline is relatively flat

- **Respite Care**
  - Benefit has been extended past prior limit of 5 days per 180 calendar days. No limit of respite is noted, but a high frequency of respite admissions may impact recertification
  - Carried out in contracted bed—SNF, Hospital, Hospice IP facility

- **General Inpatient Care**
  - Can no longer be used for “impaired home management”--these patients are now referred to respite care
  - Primarily for Terminal Care in Actively Dying patients (CMS reviews after GIC Day 7); can also be used for acute symptom management but this is unusual if patient admitted from hospital setting.

- **Continuous Care**
  - 8 hours per 24 hours beginning by 4PM for up to 5 days for home crisis management of RN or LPN services. Family must remain personally at home with these services. Designed for symptom management in situations where commitment to terminal home care exists. Less frequently seen since advent of Hospice IP facilities.

- **Fact:** Total inpatient billable days may not exceed 20% of the hospice’s total billable days for Medicare benefit patients (85% of US hospice patients are on Medicare).
Principles of Medical Ethics Decision Making

- **Autonomy**
  - Individual liberty, dignity, capacity to decide
    - Predicated on capacity of patient for self governance, understanding, reasoning, deliberating and independent choosing

- **Justice**
  - Implies fairness, what is deserved, entitled, equitable

- **Beneficience**
  - An obligation to do good
    - One should prevent evil/harm
    - One should remove evil/harm
    - One should promote good

- **Non Maleficence**
  - An obligation not to inflict harm on others
    - Do not cause offense
    - Do not cause pain and suffering
    - Do not incapacitate
    - Do not kill
Common Clinical Ethical Issues

- Principle of Double Effect
- Advanced Care Planning
- Informed Consent
- Surrogate or substituted decision making
- Treatment Futility
- End of Life Sedation
- (Assisted death) [not issue at SMMC]
Overview of Advanced Care Planning

- Determination of Preferences/Proxies
- Communication of Preferences to Others
- Documentation of preferences/proxies
- Two approaches
  - Advance Directives
    - Medical Power of Attorney (state form or custom)
    - Directive to Physician/Living Will—only activated if patient unable to make decisions
  - Physician’s order for end of life decisions
    - Inpatient DNR order/order sets /orange DNR card at DC
    - Out of Hospital (OOH) DNR order, POLST MOLST)
Goals of Care

- Any document or decisions reflect wishes expressed by the patient at the time he/she last had capacity
- Should be undertaken by an individual who is familiar with patient’s wishes, if feasible
- Should follow established order of succession:
  - Spouse
  - Reasonably available adult children
  - Parents
  - Living relative
- Should discuss alternatives that have acceptable level of double effect if straightforward decision making not applicable
Structured Family Meetings
(J. Andrew Billings, M.D., Susan D. Block, M.D., Harvard Medical School Center for Palliative Care)

- Preparation
  - Agenda
  - Setting
- Introduce the Participants, the Purpose of the Meeting and the Structure
- Assess the Family’s Understanding
- Summarize
- What Is It Like for the Patient Now?
- Explore Family’s Notions about What the Patient Would Want Under These Circumstances
  - Establish Trust
  - Substituted Judgement
- Explore and Address Family Concerns and Questions
- Frame Recommendations
  - Do not offer treatment options that are inappropriate
- Plan for follow-up
- Discuss and Document
Treatment Futility Discussions (AMA, 1992)

**Physician Obligations:**
- Offer "Medically Sound" options which
  - "cure or prevent a medical disorder"
  - "relieve distressing symptoms"
- NOT Offer non-beneficial treatments
- Patients do not have the right to demand treatments contrary to medical judgement

**Qualitative Futility**
- Clinical experience suggests clinical "hopelessness"
- Physician dependent—may be at odds with other physicians or patient/family

**Quantitative Futility**
- Probability of success or failure known from similar situations or evidence based research

**Discussion pitfalls**
- Value laden
- May lead to mistrust and disputes between caregivers, family, healthcare professionals
- Ethics committee should become involved before hardened positions develop

**ATTEMPT RESOLUTION FOR THE BENEFIT OF THE PATIENT**
Complex Situations/Withdrawal of Care

- Traumatic Accidents/Anticipatory Grief
- Referred Patient found inappropriate for referral procedure after transfer, with palliative care appropriate option
  - Applicable to Clinical Trials as well in Oncology setting
- Religious directives/practices
- Palliative Sedation
- Discontinuation of Care (Particularly Advanced Life Support) after Unsuccessful Time Limited Trial of Therapy
- Conflicts between representative/MPOA and other family members
- Advanced Planning by Primary Team, Interdisciplinary Teams and Ethics Committees, adequate Time Commitment Essential to Positive Outcome