Ethical Issues in Neuroscience Nursing: A Case-Based Approach

Dea Mahanes, MSN, RN, CCRN, CNRN, CCNS
APN 3 – Clinical Nurse Specialist, Neurocritical Care
University of Virginia Health System
Charlottesville, VA
sdm4e@virginia.edu
Disclosures

• I have no relevant relationships with industry.

• Aggregate cases based on experience.

• By definition, lots of gray....emphasis on prevention and a thoughtful approach.
Objectives

• List three ethical issues that are commonly encountered by neuroscience nurses.
• Identify two strategies that can be used in the practice setting to promote ethical decision-making.
• Define moral distress, moral residue, and the crescendo effect.
Clinical Ethics

• Ethical dilemma
  – Two or more ethically acceptable but mutually exclusive alternatives
• Guidance for clinical practice
  – ANA Code of Ethics
  – Position statements
• Variety of ethical frameworks
• Ethical principles, legal standards
Principle-Based Ethics

• Respect for persons (autonomy)
  – Right of an individual to make choices based on personal values and beliefs
• Non-maleficence
  – Avoid harm
• Beneficence
  – Take action to promote well-being
• Justice
  – Fair allocation of resources
Related Ethical Principles

• Privacy and confidentiality
• Fidelity
  – Uphold promises and commitments
• Veracity
  – Tell the truth, avoid deception
Case 1: Can this patient make a choice?

- 44 yo male, homeless, history of TBI, admitted for seizure
- Imaging reveals left frontotemporal lesion
- Neurosurgeon recommends surgical resection
- Patient refuses
- Team members question capacity
Decisional Capacity

• Grounded in autonomy
• Presumption is that patient has decisional capacity until determined otherwise
• Requirements
  – Understand relevant information
  – Understand significance for own situation
  – Engage in reasoning about alternatives and make a decision
  – Communicate that decision (but does not have to be verbal)
• Context-specific and may vary over time
• Differs from competence (legal term)
Informed Consent

• Three conditions
  – Decisional capacity
  – Relevant information provided to patient and patient must understand that information
  – Voluntary (no coercion)
Case 1: Can this patient make a choice?

• Special considerations?
  – Location of lesion, history, medication effects

• Does this patient have decisional capacity?
  – Awake, alert, oriented, frequent paraphasic errors
  – Very eager to leave hospital, sometimes agitated
  – SLP and psych involvement
  – Determined to have decisional capacity
Case 1: Can this patient make a choice?

• What happened?
  – Friend to care for dog and pick up belongings
  – Surgery completed, low grade astrocytoma
  – Discharged POD 5 with follow-up planned

• Preventive ethics...
  – Advanced medical directive
Case 2: Who decides?

- 32 yo female, admitted with anti-NMDAR encephalitis, lacks decisional capacity
- Suspected ovarian teratoma on imaging
- Team recommending removal of ovary
- Parents, boyfriend at bedside
- Parents mention that patient is also married
Identifying a Surrogate Decision-Maker

- Medical Power of Attorney or Agent for Health Care Decisions (assigned in an Advanced Directive)
- If no MPOA or Agent, based on hierarchy of relationships that varies by state
  - For example, in Virginia
    - Court-appointed guardian
    - Family, in order: spouse, adult child, parent, sibling, other relatives
    - Other adult familiar with values and beliefs (limited authority)
Standards for Surrogate Decision-Making

• Advanced directive
• Substituted judgment
  – Surrogate makes decisions based on patient’s values and beliefs about medical care
• Best interests
  – Patient’s values and beliefs are not known
  – Makes decisions based on belief of what is in the patient’s best interests
Case 2: Who decides?

- Review state law and institutional policy
- No MPOA, agent, or guardian
- Husband contacted, defers
- No adult children
- Parents agree to surgery
- Gradual improvement
But what if...

- No improvement
- Team recommends removal of other ovary
- How does the team balance the potential for improvement in neurological condition against loss of reproductive potential?
  - Evidence/clinical recommendations
  - Values and beliefs
Case 3: When the prognosis is uncertain...

- 20 yo male, T-boned and “spun” by a drunk driver at an intersection
- GCS 3 on scene, agonal respirations
- Admitted to Neuro ICU and managed per TBI guidelines
- Exam 6 days post-injury (off-sedation)
  - No eye opening
  - Minimal flexion to pain in LUE only
- MRI confirms severe diffuse axonal injury
Goals of Care and EOL Decision-Making

- Limitations of prognostication and the role of uncertainty
- Exploring values and beliefs
  - Whose values and beliefs? Patient? Family? Healthcare team?
- Nurses’ role in communication
Goals of Care and EOL Decision-Making

• Be careful with terminology when talking with families
• Acknowledge uncertainty
• Help families define pt’s values through storytelling
• Recognize your own biases
Decision-Making Models

• Paternalism
  – Clinician decides

• Informed choice
  – Clinician provides information, patient/surrogate decides

• Shared decision-making
  – Mutually agreed upon decision
Shared Decision-Making

When the prognosis is uncertain...

- Honest, open communication
- Multi-disciplinary team approach
- Individualized approach
- Admit the unknown
- Defining role of surrogate decision-maker
- Clarify values
- No right or wrong answers
- Care continues regardless of decision
- Increase time listening
- Ongoing support
Case 3: When the prognosis is uncertain...

- 20 yo male, T-boned and “spun” by a drunk driver at an intersection
- Severe DAI, GCS 1-3-1T
- In this case...
  - Trach and PEG placed
  -Transferred to TBI facility for family teaching
  - Lives at home with support
  - Severe disability
Across the continuum...
SDM Model for Outpatient Epilepsy

• Talk model
  – Team talk: support for alternatives
  – Option talk: detailed information about options
  – Decision talk: support patient, assist in making a decision

• Decision support
  – Decision aids, risk prediction, patient care plans

Case 4: “Do everything.”

- 23 yo female, multi-trauma, with severe TBI and presumed anoxic brain injury
- On ECMO, maximal vasopressor support
- Despite interventions, unable to oxygenate
- Signs of additional organ failure
- Team recommends comfort measures
- Parents want “everything”
Case 5: “Do everything”...take 2

- 59 yo male with history of severe TBI 2 years prior, MCS, seizures
- Lives in SNF, non-verbal, dependent for care, feeding tube, 4 recent hospital admissions, stage IV sacral pressure ulcer
- Admitted for pneumonia and status epilepticus
- Unable to remove endotracheal tube, worsening renal failure
- Grimaces with turns and other care measures
- Brother is decision-maker
- Decision re: tracheostomy? Hemodialysis?
Important Questions

- What is “futile” treatment?
- What is “potentially inappropriate” treatment?
- Who decides?
- Can there be a fair process for conflict resolution?
- Should clinicians have the right to make unilateral decisions about withholding or withdrawing treatments?
- Should considerations of cost enter into such discussions?
• Emphasizes prevention through proactive communication and early involvement of experts
• “Inappropriate” or “potentially inappropriate”
• Clinicians should advocate for treatment plan they believe is appropriate
• Process-based approach to conflict resolution
• Ethically inappropriate to give unilateral authority for decisions to pts/surrogates or individual clinicians

Process-Based Approach

1. Expert consultation
2. Notice of process to surrogates
3. Second medical opinion
4. Review by interdisciplinary hospital committee
5. Opportunity to transfer to another institution
6. Inform surrogates of right to extramural appeal
7. Implement decision

*If time sensitive: implement as much of process as possible, should not provide futile interventions.*

*Futile: cannot achieve desired physiologic goal.*
Case 4: “Do everything.”

- 23 yo female, multi-trauma, with severe TBI and presumed anoxic brain injury
- Unable to oxygenate
- Parents want “everything”
- What is everything?
- In this case...
  - Expert consultation
  - DNR, no escalation, family support
Case 5: “Do everything”...take 2

• 59 yo male with hx TBI, MCS, seizures
• Renal failure improves, still unable to extubate
• In this case...
  – Expert consultation
  – Ongoing discussion with surrogate
  – Pain management
  – Palliative consultation
  – Consensus decision to place trach
  – Returned to SNF
• Preventive ethics
Case 6: Coffee tastes better by mouth!

- 56 yo female admitted for treatment of basilar artery aneurysm (again)
- Incomplete obliteration of aneurysm
- Peri-procedural brainstem strokes
- Persistent dysphagia
- Declines PEG
Ethical Issues

• Should this patient be permitted to eat by mouth?
• Are the nurses ethically obligated to provide oral intake?
Approach to Refusal of Recommended Diet Modifications

• Diet modification recommended, patient refuses
  – Education, re-education
  – Assumed risk vs Real risk
    • Assumed risk – Alter recommendation, maintain recommendation, reinforce safety
    • Real risk – Consequences
  – Ongoing monitoring and follow-up
Case 6: Coffee tastes better by mouth!

• In this case...
  – SLP evaluation: “no safe oral diet can be recommended”
  – Felt to have decisional capacity
  – Education, re-education
  – Shared decision to eat by mouth with precautions as part of a palliative approach to care
  – Staff fully supportive
Case 7: Sad stories...

- 32 yo male admitted s/p anoxic brain injury
- GCS 3 at outside hospital, mother refused brain death evaluation and requested transfer
- Transferred 4 days after event
- Assessed, exam consistent with brain death
- Mother refuses to allow team to complete apnea testing
Ethical Questions

- Can surrogates refuse testing for brain death?
- How should clinicians respond to requests for continued cardiopulmonary support after death by brain criteria?
Timing of Discontinuation of Cardiorespiratory Support

“Elective ventilation”

• Ventilation without benefit to the individual

• Examples
  – While preparing for donation, or to allow time for progression to brain death
  – To allow family time to understand BD
    • “Brief period of accommodation”
  – During pregnancy, to allow fetal development
Communicating with Families about Brain Death

- Usually sudden, unexpected event
- Different kind of death - “Signs of life and signs of death”
- Pre-existing misperceptions
- Distinction between death by brain criteria, coma, and persistent vegetative state
- Concerns about motives for BD declaration
Communicating with Families about Brain Death

- Communicate openly and honestly from the time of initial hospitalization
- Seek agreement within team
- Involve supportive professionals
- Facilitate presence (including during BD testing) as desired by the family
- Offer rituals that mark the transition from life to death
Communicating with Families about Brain Death

• Avoid misleading terms and questions
  – Cannot withdraw “life support” when patient has been declared dead
  – Not a coma
  – Not a vegetative state
  – Consent not needed for DNR
Case 7: Sad stories...

• In this case...
  – Ethics, legal involvement
  – Decision to proceed with apnea testing
  – Declared dead by brain criteria
  – Mother refuses to accept declaration of death
  – Time set for discontinuation of support
  – Choices where possible
Why is it so important to address ethical concerns?
Moral Distress

Moral Distress
- Unable to take action that you think is morally or ethically right
- Internal (personal) or external (institutional) constraints keep one from taking actions perceived to be morally right

Psychological Distress
- Emotional response to a situation
- Not necessarily a violation of core values
- May co-exist with moral distress
Sources of Moral Distress

• Aggressive treatments that are unlikely to have a good outcome
• Providing care inconsistent with patient wishes
• Concerns about pain control
• Inadequate number/skill set of staff
• Ineffective team communication
• Lack of administrative support
• Etc....
Moral Residue

- Lingering effects after acute distress/situation is resolved
- Caused by repeated violations of core values or unaddressed moral distress
- Threatens moral integrity
Crescendo Effect

• Moral residue creates new “baseline”
• Each subsequent episode become additive
• Steady increase in baseline with responses becoming more pronounced
• “Here we go again”
• For clinicians, can lead to anger, depression, burnout...
Strategies to Address Moral Distress

• Support for ethical practice when conflict arises
• Preventive ethics
• Address three areas of concern
  – Patient
  – Unit/team
  – System/institution
Take home messages...

• Good ethics starts with good facts.
• Many ethical conflicts can be addressed or even avoided through skilled communication.
  – Important role for nursing
  – Use your resources
• Watch your language.
• Early recognition, early consultation.
• Take care of yourself, and take care of each other.
Selected References


Selected References, cont’d


Questions?