Ethics in PACE
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Learning Objectives:

• Discuss the unique ethical issues encountered in PACE
• Review basic principles and concepts relevant to medical ethics and how they apply to various PACE case studies.
• Outline an approach to defining, analyzing and managing ethical conflicts
• Describe the function and structure of an ethics committee (Dr. Wensel)
Ethical Theory

NORMATIVE ETHICS

• Utilitarianism (J.S. Mill): Always act so as to bring about the greatest good (happiness) for the greatest number.
• Deontology (Immanuel Kant): Always treat people as ends in themselves, never as a means only.
• Virtue Theory (Aristotle): Always act consistently with the standards of the role you play in life.
Methods of Doing Ethics

“Theory and Casuistry”

Theory

Casuistry

THEORY

CASERS

CASERS

CASERS

PRINCIPLES

EASY CASES

HARD CASE

EASY CASES
Making Ethical Decisions
A Procedural Approach

The Five R’s

Review, Respond, Reduce, Recast, Resolve
The Five “R”

1. Review the situation Identify the problem, Define the area of need
2. Respond to the issues
3. Reduce the list of possible responses
4. Recast the conflict
5. Resolve the dispute and clarify the confusion
Foundation of Ethics in Healthcare

From the Greek *ethos*

- Moral principles
- Rules of conduct
- Doing what is honorable, right and just.
Healthcare Ethics

As health care practitioners, we have an ethical responsibility to:

- Participants
- Families
- PACE organization
- Facilities

- Federal Gov
- State
- Society
- Ourselves
Healthcare Ethics

• There are times when our professional responsibilities and personal ethics may conflict and we are asked to subordinate either our principles (personal ethics) or our responsibilities.

• Bioethics provides a framework to help resolve conflict.
PACE Provider Regulations

• A PACE organization is required to develop a committee(s) with community input to 1) evaluate data collected pertaining to quality outcome measures, 2) address the implementation of and results from the QAPI plan, and 3) provide input related to ethical decision-making including end-of-life issues and implementation of the Patient Self-Determination Act. Through this committee(s), the PACE organization will be able to receive guidance regarding its QAPI program and the ethical issues faced by PACE organizations.

• [42 CFR § 460.138]
American Society of Bioethics & Humanities (ASBH)

Case Approach
- Active Case
- Requires timely response
- Input from all stakeholders
- Primary goal is resolution of conflict
- Formal written consultation

Non-Case Approach
- Retrospective
- Not time sensitive
- Input from care team
- Primary goal is education or advisory on policy
- Report on general issue
Case 1 Is he “safe”? 

- 89 year old male with dementia, severe osteoarthritis, history of syncope and MVA
- He lives alone
- Daughter lives in the area and assist with bill paying and grocery shopping
- He has had several falls but no significant injuries, walks with a cane and a limp
- He is requesting enrollment in PACE
Discussion
Case 1 Part B

- MMSE 20/30,
- He completes advance directive including HC-POA, living will and DNR
- His appoints his daughter HC-POA
- Preferences of care are functional
- He wants to die in his own home
- His home: wood burning stove, heats food, no AC, He can bath and dress himself. Tinetti score 16
Small group activity
Case 1 Part C

- He is found walking in the road when the van driver arrives to pick him up for PACE
- He initially refuses to get in the van, but he subsequently agrees
- On arrival at the PACE center he is brought to the clinic for evaluation
- Vitals signs and labs are unremarkable
The Five “R”

1. Review the situation Identify the problem, Define the area of need
2. Respond to the issues
3. Reduce the list of possible responses
4. Recast the conflict
5. Resolve the dispute and clarify the confusion
Problems/areas of need?
Respond: Call daughter

Placement
Extra CNA
Move in with daughter
Daughter move in with him

Recast and resolve
Case 1: the ethical dilemma

• Participant appears to be comfortable at home
• Team feels that he needs more supervision
Healthcare Ethical Principles

• Autonomy
• Beneficence
• Nonmaleficence
• Justice
Autonomy

• The right of self-government, personal freedom and freedom of will.

• Ethical Principle: Having, acknowledging and showing respect for a person’s right of self-determination regarding his/her life, body, mind, and spirit (including medical care).
Beneficence

• The act of doing good, being generous and actively being kind.

• **Ethical Principle**: The obligation to do good and act in the best interest of others.
Non-maleficence

• Not being hurtful to others.

• **Ethical Principle**: The obligation to avoid harming others.
Justice

• Just conduct, fairness.

Ethical Principle: The duty to treat individuals fairly and without discrimination and to distribute resources in a non-arbitrary and fair manner.
Fidelity

• Faithfulness, loyalty
• Strict conformity to truth or fact.

• Corollary Ethical Principle: The duty to keep promises.
Ethical Theory: Summary

• Four key ethical principles for healthcare decision making and conflict resolution of ethical/clinical dilemmas.
  – Autonomy
  – Beneficence – “do good to others”
  – Nonmaleficence - “do no harm”
  – Justice - “treat others fairly”
Other Related Issues

• Paternalism
  – “Do what I say even though you don’t want to, because I know better than you and I have decided that [this] is good for you and is what you should do.”
  – Counter to the principle of autonomy.
  – Not an ethical principle.

• Confidentiality

• Privacy, dignity

• Truth, duty, responsibility
Decision Making Capacity (DMC)

• Describes an individual's ability to make practical decisions in his or her own interest.
• Can be health-related and/or financially related.
• Not same as judicially defined status of “competent” or “incompetent.”
Participant’s DMC

• Does the participant have the capacity to make the decision for him/herself?

• If so, we have to abide by the participant’s decision.
Case 1 Part D

• He develops seizure disorder characterized by acute prolonged unresponsiveness
  – Do we admit him to the hospital?
  – Arrange social respite?
  – If he does return home, how do we manage home medication administration?
Framework for Ethics Case Discussion

• What is the source of moral distress?
• What are the key factors?
• Who are the key stakeholders?
• What is the decision to be made?
• What ethical value/norms are involve?
• Does an option exist that bypasses the conflict?
• How are the conflicting ethical values balanced/prioritized?
• What is the ethical recommendation?

Adam Burrow, MD
Highlights in Ethics

• 1847 Code of Ethics from the AMA
• 1914 Law established for patient consent
• 1950 Biomedical ethics begins as a discipline in US
• 1960’s consumer rights movement
• 1967 Attorney Luis Kutner suggested the creation of Living Will

Hussain, Kumar and Gambert, Advance Directives Revisted, Clinical Geriatrics, February 2013
Natural Death Act

• 1976 Barry Keen California
• 1976 Joe Quinlan granted the right to make healthcare decision for his daughter: Karen Ann (3/29/54- 6/11/85), New Jersey
• 1992 Advance Directives were legalized in all 50 states and the District of Columbia
Patient Self Determination Act

• On January 11, 1983, Nancy Cruzan lost control of her car. She was thrown from the vehicle and landed face-down in a water-filled ditch. Paramedics found her with no vital signs, but they resuscitated her. After three weeks in a coma, she was diagnosed as being in a persistent vegetative state (PVS). Surgeons inserted a feeding tube for her long-term care.

• December 1, 1991
Advance Directives

• Living Wills
• Durable Power of Attorney for Healthcare
• POST, POLST, MOST
• 5 Wishes
• Go Wish Game (www.gowish.org)
Advance Directives for Health Care

Definition:
• Formal or informal statements of a person's philosophy and instructions for health care made in advance of incapacity to make such decisions or to effectively communicate choices.
Advance Directives: Legal and Regulatory Foundation

- Patient Self-Determination Act 1991
- Autonomy principle
  - Basic right to execute Advance Directives and have them honored.
- Premise for substitute decision maker (SDM)
  - Authorization of other individuals to act on behalf of someone who can no longer act autonomously.
- Providers and practitioners
  - Duty to inform of rights and offer support for patient decision making.
Case 2

- 96 female with advance dementia, severe DJD with impaired ambulation
- Primary care giver is nephew.
- 6 months after enrollment the nephew is killed
- Niece becomes POA
- Niece and the participant do not get along
Problems in Interpreting and Applying Advance Directive

• Absence of any written instructions for care;
• Insufficient clarity or specificity;
• Inadequate patient or SDM; understanding (of care options or implications of choices);
• Problems related to SDM;
• And cultural differences.
Challenges to Advance Directives

• Some family members or team members may dispute AD.
  – Try to contradict AD by stating that individual didn’t understand, didn’t know what they were doing, or would do something different now.

• Valid ADs are best available representation of individual values and wishes.
Substitute Decision Maker (SDM): Criteria for Serving

• Usually, but does not have to be, next-of-kin.
• Sometimes, no one named to make decisions on behalf of incapacitated individual.
• Substitute decision maker may either be appointed or assume role by default.
Succession of SDMs

• Guardian or SDM specifically appointed in an AD (often called a surrogate or agent) take precedence over others.

• When no one appointed by patient or courts, most states specify succession of SDMs.
  – Spouse, adult child, parent, adult sibling, close friend (e.g. hierarchy of decision making)
Succession of SDMs

• Most states permit designation of an alternate SDM if primary SDM unavailable or unwilling to serve.

• SDM’s authority may be limited, depending on decision.
  – e.g., withholding life-sustaining treatments, DNR
Substitute Decision Maker Tasks

• Should honor advance directives.
• Where guidance inadequate, use “best interest” criterion.
• Qualifying conditions (end-stage, terminal, or persistent vegetative state) sometimes required to allow SDM to withhold or withdraw life sustaining treatments.
Potential Conflicts Among SDMs

• Authorized individual may disregard input from others.
• Multiple decision makers.
• Some states require all surrogates in a given class to agree (or at least not to dissent).
• Unresolved conflicts.
• Cultural Differences: Some family members may follow the ethnic traditions, while others may be more Westernized in their views.
Guardianship

• A person or entity appointed by the courts to exercise all of the powers and duties necessary for the care of an incapacitated person (some limitations may exist).

• Occurs when there is no legal substitute decision maker and the person lacks capacity.
Responsibilities of the provider in managing ethical issues
Ethical Dilemmas in PACE

Driving
- Code Status

Enrollment
- Disenrollment
www.chossing wisely.org
Clarify Medical Condition and Prognosis

• Patient’s ability to participate in process.
• Potential medical effectiveness and risks of various treatment options.
  – Based on medical condition and prognosis.
• Help staff identify ethical relevance of treatment options.
  – Based on patient’s values and wishes.
Define Treatment Options

• What treatment options should be identified?
  – Short-term vs. long-term situations

• Whether aggressive medical treatment is desired for serious acute illnesses.

• Whether diagnostic testing is desired to assess condition changes.

• Whether to hospitalize for more complex situations.
How Successful Is CPR in Older Patients?

By **PAULA SPAN** August 9, 2012 1:12 pm
Case 1
  • Decision making capacity limited but intake
  • Care giver support limited
  • Impaired mobility

Case 2
  • DMC lacking
  • Care giver support limited
  • Impaired mobility
Ethics Committees - Purpose

• Education
  – Of the committee about ethical principles, laws, regulations, policies, procedures, and common ethical dilemmas.
  – Review of clinical literature relevant to ethics decision making.
    • Example: Medical factors that predict prognosis.
  – Of facility staff, residents and families, and the greater community.
Ethics Committees - Purpose

• Values clarification
• Development of policies and procedures concerning handling of ethical dilemmas.
• Quality assurance activities to ensure that policies and procedures are implemented and followed.
• Consultation
Ethics Committees - Composition

• Administration
• Clinical: physician / nursing / rehab / dietary
• Support: Social work / nursing assistant
• Clergy
• Legal counsel
• “Community”
  – Be clear about what you wish community member to bring to the committee.
PACE Ethics Committees

• Sponsoring organization
• Formed independent committee
• Formed joint committee*
Rural PACE Virtual Ethics Committee

• Six rural PACE sites
• Membership
  – From each participating PACE site
  – Community representative
• Chair/facilitator
• Meetings
Ethics Committees - Process

• Available to patients, family, and staff
• Serves in advisory capacity, making non-binding recommendations.
• Documentation may not be protected from discovery.
  – Avoid names and identification.
• May be “shared” with other institutions.
Ethics Committees - Issues

- Capacity for decision-making
- End-of-life care
- “Non-compliance”
- Family conflict
- Patient rights / autonomy
- Sedation / restraints
Ethics Committees
Case Review

• Physician referral
• Family or patient issues
• Nursing/caregiver concerns and “stresses”
• Unexpected/undesired outcomes
Successes and Pitfalls

• Keeping clarity of purpose.
• Maintaining involvement.
• On-going committee evaluation.
• Expense
• Should support willingness of physician/family to make decisions.
• Potential for adversarial situations.
Internal Resources to Help PACE teams With Decision Making

• Ethics committee
• Quality assurance committee
• Participant Advisory Committee
External Resources to Help PACE teams With Decision Making

• Ombudsman
• Clergy
• Bioethics literature/consultation
• Alzheimer’s Association
• Hospice
• Community ethics committees
• Pertinent state law and regulation
Research in PACE

• Clinical research may present ethical conflicts.
• Informed consent for an IRB-approved protocol is basis for ethical inclusion of PACE participants in a clinical trial.
• Ethical dilemmas arise when incapacitated persons are enrolled in a research protocol.
Summary: Physician Responsibilities

- Adequate participation in key steps of decision-making process.
- Help IDT members understand factors involved in ethics and decision making.
- Clarify risks and benefits of life-saving technologies and treatment options.
IDT Responsibilities

• Help reconcile and balance interests of patient families, team members and the PO
• Help address patient and family concerns, issues related to advance care planning.
• Help maximize participant autonomy.
Summary: IDT Responsibilities

• Establish and policies and procedures
• Ensure adherence to laws and regulations.
• Respect the values, beliefs and rights of the patient
• Utilize ethics committee when available
Summary

• Healthcare ethics (theory) provides a construct to help patients, families and practitioners resolve conflicts in provision of care.
Thank you

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