Ethical Issues in PACE

PACE Basics Workshop

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What is an Ethical Dilemma?

- Decision about what one *should* or *ought* to do
- Two (or more) ethically justifiable options
- Good, persuasive arguments for and against each option
- Must choose one
- Ethical dilemma = ethical conflict = moral conflict
Moral Distress

Moral Conflicts  \rightarrow  Moral Distress

Team struggling with a difficult case
Team uncertain about *what it should do*
Team divided about *what it should do*
Members of team feeling pressured or uncomfortable

Friedson 2011
PACE Provider Regulations

- PACE Final Rule, Section 460.138 (c)
- A PACE Organization must establish (a committee) with community input to … provide input related to ethical decision-making, including end-of-life issues and implementation of the Patient Self-Determination Act
PACE Ethics Committees

- Structure?
- Composition?
- Role?
- Responsibilities?
- Issues?
- Meetings?
Ethics Committees

• Functions
  - Consultation
  - Education
  - Policy

• Focus
  - Clinical Ethics
  - Organizational Ethics
  - Preventive Ethics
Massachusetts PACE Ethics Committee

- 3 PACE Organizations
  - 12 PACE Centers/Teams
  - 1500 PACE Participants

- Committee Membership
  - Permanent Members
    - Philosophy (Chair)
    - Law
    - Gerontology
    - Nursing
  - Participating PACE Organizations

- Meetings
  - Monthly Meetings
  - Central Location
  - Case Presentations
    - PACE Organizations Rotate Cases
    - Cases Distributed in Advance
    - Maintain Anonymity & Confidentiality
Rural PACE Virtual Ethics Committee

- 8 Rural PACE Organizations
- Committee Membership
  - PACE Clinicians and Managers
  - Community Representatives
    - Clergy
    - Philosophy
    - Theology
    - Nursing
  - Chair/Facilitator

- Meetings
  - Semi-monthly
  - Phone Conference
  - Case Presentations
    - PACE Organizations Rotate Cases
    - Cases Distributed in Advance
    - Maintain Anonymity & Confidentiality
PACE Ethics Committee

• Function
  - Advise PACE Organizations
    • Guidance on Specific Cases/Situations
    • Help Resolve Ethical Dilemmas/Conflicts
  - Promote Ethical Awareness
  - Educate PACE Teams
PACE Ethics Committee

• Educational approach to consultation
  - Active or retrospective case
  - Input from members of the care team
  - Forum for discussion
  - Primary goal is educating team so it is able to reach and justify an ethically sound decision
  - Informal recommendations
  - Care planning advice
  - Documentation for educational purposes
SFNO Framework

- Stakeholders
- Facts
- Norms
- Options
Stakeholders

• Parties who may have competing interests
  – Patient
  – Family/caregivers
  – Team members
  – Organization
  – Other providers
  – State
  – CMS
  – Local community
  – Society at-large (public health, taxpayers)
Facts

• Examples of ethically relevant facts
  – Medical Facts
    • Medical problem
    • Prognosis
    • Treatment options
  – What are the member’s goals and preferences?
  – Decision to be made
    • Is the problem/decision ethical?
  – Who has decision-making authority?
  – What laws/regulations apply?
    • What are the consequences of violating them?
Norms

Where do our norms come from?

• Four Ethical Principles
  - Autonomy
  - Beneficence
  - Non-maleficence
  - Justice
Norms

• Other Values
  - Loyalty
  - Honesty
  - Commitments
  - Respect
  - Privacy
  - Confidentiality

• Professional Codes
• Organizational Values
• Religious Directives
• Cultural & Religious Beliefs
Options

• Does an option or compromise exist that bypasses the source of disagreement?
• Examples of options
  – Outside consult
  – Time-limited trial
  – Transferring care
• What is the ideal choice?
Framework for Case Discussion

• What is the source of moral distress?
• What are the key facts?
• Who are the key stakeholders?
• **What is the decision to be made?**
• What ethical values/norms are involved?
  - Conflicts among values
  - Priorities to different values
• Are there options that bypass the conflict?
• Ethical recommendation
• Care-planning advice
Ethically Relevant Features of PACE Model

- **Mission**
  - Community-Based Long-Term Care
  - “Subvert the Institutional Paradigm” (Phil Fleischer)
- **Financing**
  - Managed Care
- **Enrollment**
  - Any Eligible Participant
  - Lifelong Commitment
- **Team**
  - Potential for Disagreement
- **Intimacy**
- **End-of-Life Issues**
Place of Death in PACE

- Hospital: 21%
- Home: 34%
- Nursing Home: 45%

Older Americans: 53%
Case #1
Autonomy in the PACE Model

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Ethical Principles

• Autonomy
  - vs. Paternalism
  - Informed Consent
• Beneficence
• Nonmaleficence
• Justice
Informed Consent

- Responsibilities of Clinician
  - Nature of Problem
  - Proposed Intervention
  - Alternative Approaches
  - Risks & Benefits
Decision-Making Capacity

• Decision-Specific Capacity
  - vs. Competence
    • Global
    • Legal

• Meet Standard of Informed Consent

• Standard Proportional to Risk
  - High Risk - High Standard
  - Low Risk - Low Standard
Assessing Capacity

• Can the Patient Give Informed Consent?
  - Expresses Appreciation of Situation
  - Understands Consequences of Decision
    • Risks & Benefits
  - Manipulates Information
  - Reasons Coherently & Consistently
  - Paraphrases
Advance Directives

• Goal
  - Protect Autonomy When The Patient Loses Capacity

• Approaches
  - Surrogate Decision-Makers
  - Decision-Specific Documents

• Patient Self-Determination Act of 1990
Surrogate Decision-Makers

- Durable Power of Attorney for Health Care
  - Health Care Proxy
  - Health Care Agent
- Massachusetts Health Care Proxy Law
- Legal Guardian
Decision-Specific Documents

• Living Wills
• Health Wishes
  - Resuscitation
  - Mechanical Ventilation
  - Feeding Tube
  - Hospitalization
• Care Pathways
State laws on advance directives
States that authorize living wills and the appointment of a health care proxy, 2007

- States that allow both living wills and the appointment of a health care agent
- States that allow only the appointment of a health care agent

Source: State Advance Directive Download, 2007, Caring Connections (National Hospice and Palliative Care Organization)
Decision-Specific Documents

- POLST
  - Physician’s Orders for Life-Sustaining Treatment
- Massachusetts MOLST
  - Medical Orders for Life-Sustaining Treatment
### Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST)

**Patient's Name**

**Address**

**Date of Birth**

**Gender**

Print name and phone # of Patient's Primary Care Provider, if available:

- Sections D and E must be fully completed for a valid form; photocopy, fax or electronic copies of signed MOLST forms are valid.
- If a section is not completed, there is no limitation on the treatment indicated in that section.
- This form is effective immediately upon completion. Send this form with the patient at transfer or discharge.

#### Every Patient Should Receive Full Attention To Comfort

<table>
<thead>
<tr>
<th>A</th>
<th>Select one box</th>
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<tbody>
<tr>
<td><strong>Cardiopulmonary Resuscitation</strong>: for a patient in cardiac or respiratory arrest</td>
<td></td>
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<td>☐</td>
<td>Do Not Resuscitate</td>
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<td>Attempt Resuscitation</td>
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<td><strong>Intubation and Ventilation</strong>: for a patient in respiratory distress</td>
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<tr>
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<td>Do Not Intubate and/or Ventilate</td>
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<tr>
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<td>Intubate and/or Ventilate</td>
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<tr>
<td><strong>Transfer To Hospital</strong>: (unless stated to comfort)</td>
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</tr>
<tr>
<td>☐</td>
<td>Do Not Transfer to Hospital</td>
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<tr>
<td>☐</td>
<td>Transfer to Hospital</td>
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#### Signed in section D by:

- Check one box to indicate who is signing.
- ☐ the patient, or
- ☐ guardian*, or
- ☐ health care agent, or
- ☐ parent/guardian* of a minor patient.

- A guardian can sign to the extent permitted by Massachusetts law. Consult legal counsel with questions about a guardian's authority.

**Signature of patient, health care agent, guardian* or parent/guardian* of minor patient**

**Date of Signature**

Print name and contact number(s) for person signing Section D

#### Signed in Section E

- **Signature of Physician, Nurse Practitioner (NP) or Physician Assistant (PA)**
- Signature confirms this form accurately reflects discussion(s) with Section D signer

**Date of Signature**

Print name and contact number(s) for person signing Section E

#### Record of Periodic Review:

- Upon review, if an change to this form is needed, the Physician, NP or PA should sign and print name and contact number(s) below.

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Surrogate Decision-Making

• Framing the Question
  - Substituted Judgment
    • What would your mother choose if she could decide for herself?
  - Best Interest
    • What do you think is best for your mother?

• Advantages of Substituted Judgment
  - Respects Autonomy
  - Reduces Burden on Surrogate
Decisions in Everyday Geriatrics

- Medical Interventions
- Managing Financial Affairs
- Long-Term Care Options
  - Nursing Home vs. Community-Based Care
  - Safety vs. Risk
    - “Differing Views of Safety Are at the Root of Ethical Conflicts in Long-Term Care” (Rosalie Kane)
    - Physical vs. Psychosocial Safety (Bart Collopy)
  - Apply Principles of Informed Consent
Psychosocial Safety & Risk

- Psychosocial Safety
  - Continuity With Past
  - Familiar Routines & Places
  - Mix of Order & Spontaneity
  - Self-Esteem
  - Preservation of Meaning
  - Ability to Keep Life From Unraveling in the Face of Frailty and Disability

- Psychosocial Harm
  - Harms to Mind & Spirit
  - Fractured Living Patterns
  - Emotional Pain
  - Social Disability
  - Dislocation
  - Loss of Control

Colopy BJ. Safety & Independence. in Long-Term Care Decisions. 1995
Safety vs. Risk

• What is Safety? (Bart Collopy)
  - Physical vs. Psychosocial Safety
  - Values History
    • Hierarchy of Safeties
• Dignity of Risk (Robert Perske)
• Illusion of Physical Safety
• Mitigate vs. Eliminate Risk
  - “Partial Solutions” (Bart Collopy)
Case #2
Involuntary Disenrollment in PACE

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Involuntary Disenrollment

- PACE Final Rule, Section 460.164
- Involuntary Disenrollment
  - State Must Review and Accept Disenrollment
  - Non-Controversial Situations
    - Failure to Pay Premiums
    - Moving Out Service Area > 30 Days
    - No Longer NHC Level of Care
    - Termination of PACE Program
Involuntary Disenrollment (Section 460.164 (b))

• Ethically Relevant Situations
  - *Disruptive or Threatening Behavior*
    • “Participant who engages in behavior that jeopardizes his or her health or safety, or the safety of others”
  • Organization must document reasons for disenrollment and all efforts to remedy the situation
Involuntary Disenrollment (Section 460.164 (b))

• Ethically Relevant Situations
  - Non-Compliant Behavior
    • “Participant with decision-making capacity who consistently refuses to comply with individual plan of care or terms of enrollment agreement”
    • Behavior cannot be due to mental or physical condition
      - Unless behavior jeopardizes his or her safety or the safety of others
    • Includes “repeated non-compliance with medical advice and repeated failure to keep appointments”
Is Involuntary Disenrollment an Ethical Issue?
Why Is Involuntary Enrollment An Ethical Issue?

- Autonomy
  - Right to Refuse Treatment
    - Freedom from Coercion
  - Right to Make Bad Decisions
    - Smoking, Drinking, Eating
    - Declining Medical Treatments
  - Values History
Why Is Involuntary Enrollment An Ethical Issue?

• Beneficence
  - PACE Enrollment Commitment
  - Is PACE Helping the Patient?

• Nonmaleficence
  - Would the Patient be *Better* Off Without PACE?
  - Might the Patient be *Worse* Off Without PACE?
Why Is Involuntary Enrollment An Ethical Issue?

• Justice
  - Global Budget
  - Distribution of Limited Resources
  - Principle Violated Only if Care of Others is Actually Threatened
Our Approach

• Involuntary Disenrollment Justified Only If
  - Others are at risk of harm
    • Other Participants
    • Staff Members
• Fulfill Clinical & Ethical Responsibilities
  - Advise, Counsel, Earn Trust
  - Principle of Informed Consent
  - Negotiate Partial Solutions
  - Resist Temptation to Disenroll