

FHCDA and Ethics Review Committee Training

A Relational Framework for End of Life Decision Making:

Understanding and Implementing New Law and Policy in New York State

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Project Team

We have no conflicts of interest to disclose.

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Opening Remarks



- Define Medical Futility
- Review factors that lead to futile situations
- Communicate and negotiate conflict resolution
- Describe a fair process to resolve intractable conflict



Is this a case of medical futility?



- Unequivocal cases of medical futility are rare
- Miscommunication common
- Value differences common
- Case resolution more important than definitions



What Futility Is

- Cannot achieve the patient's goal
- Serves no legitimate goal of medical practice
- Ineffective more than 99% of the time
- Does not conform to accepted community standards



What Futility is Not



- Things that are impossible, implausible
- Not just description, but operational
- Distinguish from hopelessness
- Not an argument to limit resources



Care vs. Treatment



- Care is never futile.
- Certain treatments, under specific circumstances, may be inappropriate and futile.



Conflict over treatment

- Unresolved conflicts lead to misery
 - most can be resolved
- Try to resolve differences
- Support the patient / family
- Base decisions on
 - informed consent; advance care planning; the patient's values, beliefs and goals for care; and shared, informed decision-making



Shared, Informed Medical Decision Making



- Will treatment make a difference?
- Do burdens of treatment outweigh benefits?
- Is there hope of recovery?
 - If so, what will life be like afterward?
- What does the patient value?
 - What is the goal of care?



Core Patient Values & Beliefs



- What makes life worth living for the person?
- What really matters to the person?
 - Participation in meaningful relationships
 - Not to be a burden to loved ones
 - Avoidance of severe discomfort
 - Relief of suffering
 - Improvement or maintenance of quality of life
 - Maintenance of personhood
 - Achieve a good death
 - Support for families and loved ones



Goals for Care



- **Longevity:** “do what is necessary to keep me alive”
- **Functional preservation:** “I am currently meeting my core values. However if a condition occurs in which I am not likely to recover to meet my core values, I would not want treatments to extend my life and request a change to focus on comfort care.”
- **Comfort care:** “I am currently not meeting my core values and have a poor quality of life. Focus solely on my comfort. Longevity at this point may increase my suffering.”



Differential Diagnosis

- Inappropriate surrogate
- Misunderstanding
- Personal factors
- Values conflict



Surrogate selection

- Patient's stated preference
- Legislated hierarchy
- Who is most likely to know what the patient would have wanted?
- Who can reflect the patient's best interest?
- Does the surrogate have the cognitive ability to make decisions?



Misunderstanding: Causes

- Diagnosis unknown...too much jargon
- Different or conflicting information
- Previous overoptimistic prognosis
- Stressful environment
- Sleep deprivation
- Emotional distress
- Psychologically unprepared

Inadequate cognitive ability



Misunderstanding: Response

- Primary communicator
- Information in small pieces, multiple formats
- Use understandable language
- Frequent repetition may be required
- Assess understanding frequently
- Do not hedge to “provide hope”
- Encourage writing down questions
- Provide support
- Involve other health care professionals



Personal factors

- Distrust
- Guilt
- Grief
- Interfamily issues
- Secondary gain
- Physician / nurse



Values Conflict

- Disagreement re:
 - goals for care
 - relative benefit of treatment

- Difference in values
 - religious
 - miracles
 - value of life



Process Steps to Achieve Conflict Resolution



- Earnest attempts in advance
- Shared, informed medical-decision making
- Negotiation of disagreements
- Referral to ethics committee, as needed
 - Conflict resolution
 - Meet legal requirements of FHCDA
- Transfer of care to another physician
- Transfer to another institution



Summary of Needs Assessment



- Futility is not straightforward
- Limitations of futility definitions
- Factors that lead to futile situations
- Use process to communicate and negotiate conflict resolution using the patient's core values and goals for care
- Outline a relational framework for end-of-life decision-making as part of FHCDA and Ethics Review Committee Training



Objectives



- Demonstrate need for a paradigm shift in end of life decision making and caregiving—an “individualistic paradigm” vs. a “relational paradigm”:
 - From “transactional” decision making to communicative decision making
 - From adversarial autonomy to relational values
 - From an individualistic to an ecological conception of end-of-life care
- Assess where we are now:
 - Review Ethical/Legal Framework for end-of-life decision making and care
 - Identify unresolved problems in applying the framework in clinical settings
- Envision where we need to go and how to get there:
 - Discuss possible future approaches to improving end-of-life care for patients and families
 - Recent changes in law and policy
 - Challenges in implementing new requirements and approaches
 - Complexity in decision making



Some Historical Benchmarks



- 1968: Harvard criteria for brain death
- 1973: First US Hospice program
- 1975: California Natural Death Act (Living Wills)
- 1976: Quinlan case-New Jersey
- 1980s: Major cases in New Jersey, Massachusetts, New York, California
- 1983: Medicare Hospice Benefit
- 1989: Cruzan case-US Supreme Court
- 1990: Dr. Jack Kevorkian gains notoriety
- 1990s: Advance directive statutes; DPAHCs; hospital ethics committees
- 1990s: State referenda to legalize PAD; Oregon enacted in 1996 ; Washington enacted in 2008 on second attempt
- 2005: Schiavo case-Florida; nationwide controversy
- 2005: NYSDOH Authorization to use MOLST in ALL healthcare facilities in NYS
- 2008: NYSDOH Authorization of MOLST in ALL settings in NYS
- 2010: New York Family Health Care Decisions Act and NYSDOH-5003 MOLST Form
- 2011: New York Palliative Care Information Act



Where are we now:

Points of Legal and Ethical Consensus



- Patients with decision making capacity have a common law and a Constitutional right to refuse medical treatment, including life-sustaining medical treatment.
- Incapacitated patients have the same rights as patients with capacity; however, the manner in which these rights are exercised is different.
- In general, the right to refuse life-sustaining medical treatment does not depend on the patient's life expectancy. This right is not limited to those deemed to be "terminally ill."
- There is no ethical difference between withholding or withdrawing life-sustaining medical treatment.
- Artificial nutrition and hydration is a medical treatment and may be withheld or withdrawn under the same conditions as any other form of medical treatment.
- In making decisions for incapacitated patients, surrogate decision makers should apply the following standards (in order):
 - Subjective standard (follow the patient's advance wishes, verbal or written)
 - Substituted judgment (infer what the patient would want from background knowledge and relationship)
 - Best interests (do what a reasonable person would want and would benefit from)
- It is acceptable to provide pain medication sufficient to control a patient's pain even if that may foreseeably hasten the patient's death.
- Active euthanasia and assisted suicide are morally and legally distinct from forgoing life-sustaining treatment. The right to refuse life-sustaining treatment does not entail the right to be assisted in committing suicide.



Problems with the Individualistic Paradigm: The Burden of Advance Directives



- Emphasis on individual autonomy makes surrogate decision making problematic. The upshot is emphasis on expressions of patient preferences and values while capacitated—Advance directives and advance care planning. We have failed to integrate advance directives into more comprehensive advance care planning and case management.
- Problems:
 - Limited use of Advance Directives and difficulty implementing advance care planning.
 - Too often ADs are not done at all
 - When done, often not done well. Treatment directives are too vague. Health care agents/surrogates are not well prepared or supported in their responsibilities.
 - Even if created, advance directives are not always followed. Problems of record keeping and continuity of care (cf. later discussion of MOLST)



Partial solution: Family Health Decisions Act

Problems with the Individualistic Paradigm: Medical Futility



- Difficult to define
 - Broad and narrow definitions (quality of life/physiological)
 - Narrow definitions do little to prevent overly aggressive treatment.
 - Broad definitions seem to give too much power to physicians.
- Family misunderstanding
 - Don't recognize the costs and burdens of “trying” unlikely treatments.
 - Psychological barriers—hope, guilt, loss, mourning.
- Whom do you trust? Financial conflicts of interest in the background.



Problems with the Individualistic Paradigm: Cultural Diversity



- Protecting rights vs. respecting diversity
- Universal ethics or WASP/middle class bias?
- What is rational?
- What is autonomy?
- Is there a right not to plan?
- Mistrust and the underserved



Problems with the Individualistic Paradigm: Are quality of life judgments wrong and unjust?



- Original intent was to create a subjective, person-centered decision making process; one that is neutral and does not impose third party quality of life judgments. But is there hidden bias in the decision making process?
- Are advance directives nothing more than biased quality of life judgments imposed by a past, able-bodied self on the present, impaired self?
- Do cultural biases against dependency and impairment compromise the valid autonomy and informed consent upon which the right to refuse treatment is based?



Core Elements of a Relational Paradigm



- Shared, informed medical decision making
- Communication that is culturally and family appropriate
- Decision making that is not ad hoc but instead centered around an advance plan
- Continuity of care across the continuum of care



Advantages of a Relational Paradigm



- It responds to the overall condition of the person (not just disease or the symptoms of the patient) —the person in social, relational context, not the individuated body.
- It provides continuity of care and manages transitions well.
- It integrates caregiving, community, and culture (meaning).



Background Assumptions of the Relational Paradigm



- Rights are relational
- Humanistic perspective: humans beings are fundamentally social and relational
- Social ecological context: nexus of social and cultural relations among human beings
- Decision making involves cognitive, affective and communicative dimensions



Facilitated Communication and Decision Making: New Roles for Ethics Committees



- New responsibilities are emerging:
 - From a consultation model to a more authoritative role
 - Requirements for membership and procedure (FHCDA)
 - Binding rather than advisory authority (FHCDA)
- Facilitating communication and consensus:
 - Mediation and conflict resolution
 - Timely and appropriate intervention
 - Relationship to other processes such as palliative care consultation



Important New Laws and Policies in New York



- Family Health Care Decisions Act (June 1 effective date)
- MOLST Program (DOH-5003 Form June 1 effective date)
- Palliative Care Information Act (February 2011 effective date)



Challenges of Interpretation and Implementation



- Interpretation: What does the law mean and for whom?
- Implementation: bridging policy and practice; creating organizational structure to carry out policy goals and to comply with laws
- Therapeutic Jurisprudence: identifying intended beneficiaries of law and policy; understanding law as lived, as social practice; gaps between policy and practice.



Care Continuum and Care Transitions



- Hospital/ICU
- Long Term Care/Nursing Homes
- Community Based Agencies – Hospice, Home care
- Home
- Regional variations in supply and in practice which influence care



Levels of Decision Making



- Systems-wide Level Decisions (e.g., proposed recommendation by Fiscal Commission to limit Medigap coverage for cost sharing; Arizona state government decision to limit eligibility of Medicaid recipients for organ transplants)
- Provider/Systems Level Decisions (e.g., limiting eligibility to certain units or programs of care)
- Individual Decision Making:
 - Patient, Health Care Agent, Surrogate



Formulation of Internal Provider Policies



- Templates
- Essentials of good policies – facility specific, role-specific, mapping out of responsibilities
- Best practice – consultation, vertically and horizontally; across disciplines
- Education and training – *sine qua non* of effective implementation



Decision Making at an Individual Level



- Decision Making Process
- Steps of process
- Valuing and affective dimensions of process



Decision Making Process



- Information about treatment choice, alternatives and consequences
- Attention to treatment choice and alternatives
- Discussions, conversations, counseling, communication
- Willing, deliberating and choosing – valuing involved in this process; affective dimensions
- Communication of decision



Example 1: Artificial Nutrition and Hydration



What is involved in forgoing treatment?

Key elements of a discussion with agent/surrogate/family

Treatment: PEG Tube Feeding for a patient with advanced dementia

Treatment Choices: (a) Surgical placement of PEG Tube to prolong life or (b) Forgoing Tube Feeding in favor of a palliative treatment plan

Alternatives to Tube Feeding: Comfort feeding by hand, palliation of any symptoms of dehydration (ice chips; mouth care, etc.)

Prognosis/Consequences of Decision: medical prognosis/life expectancy; conditions of life—symptoms and side effects, treatment for concurrent conditions, relational implications, use of restraints

Values involved in the treatment choice (e.g. continued life, dignity, suffering, respect for personal autonomy, best interests)



Example 2: Leg Amputation

What is involved in forgoing treatment?

Key elements of a discussion with agent/surrogate/family

Treatment: Limb amputation for patient with advanced vascular disease for gangrenous condition of leg determined by physician to be incurable or irreversible condition.

Treatment Choices: (a) Surgical amputation or losing limb, or (b) Forgoing surgical amputation.

Alternatives: pain management and palliative care; limb necrosis medical and nursing management.

Prognosis/Consequences of Decision: medical prognosis/life expectancy; conditions of life—symptoms and side effects, treatment for concurrent conditions, relational implications, rehab prospects and intensity of care implications; meaning to patient of body and social identity.

Values involved in the treatment choice (e.g. continued life, dignity, suffering, respect for personal autonomy, best interests).

Complexity of decision and valuing process involved in this example.



Ethical Issues in Decision Making Process



- Agency – how do we define it, who has agency (e.g., persons with in varying stages of dementia), how is it meaningful?
- For those without capacity, is the concept of agency relevant? Do the values and preferences of the incapacitated person have stability over time? If not, what is the ground of obligation, moral action?



FHCDA Clinical Criteria



Authorizes surrogates to make decisions to withhold or withdraw life-sustaining treatment, **including DNR Orders**, if one (or both) of the following conditions apply:

- Treatment would be an extraordinary burden to the patient **and** attending physician determines, with independent physician concurrence, that patient is terminally ill (expected to die within 6 months) or permanently unconscious; or
- Treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances **and** patient has an irreversible or incurable condition, as determined by attending physician with independent physician concurrence.



Interpreting Standards/Operationalizing in Different Care Settings



- How to parse standards
- Assessment of burden
- Role and responsibility of surrogate
- Role and responsibility of physician
- *Is there a role for the interdisciplinary team?*
- Issues specific to care settings and to care transitions



Ethical issues in negotiation and resolution of conflict



- Role of family in decision making
- Role of health care professionals in assessment of family members' burden
- Ethical obligation to address conflict arising within family in decision making process - parameters
- Legal duties and responsibilities
- Structure/role of ethics committee – systems-wide, ethics consultations
- No prescriptions for ethical decision making



Functions of Ethics Committees



- FHCA requires hospitals and nursing homes to establish or participate in an ethics review committee that meets certain standards (e.g., interdisciplinary membership), and to adopt a written policy governing function, composition, procedure.
- Function: ***“The ethics review committee shall consider and respond to any health care matter presented to it by a person connected with the case.”*** Section 2994-m.2.(a).
- Committee responses may include providing advice on ethical issues, making recommendations, or providing assistance in resolving disputes about proposed health care.
- Advice is advisory/nonbinding except in mandated reviews.



Mandated Reviews of Ethics Committees



Certain life-sustaining treatment decisions require ethics committee review and in these cases, the committee must agree that the decision meets the FHCDA standards :

- ✧ Surrogate decisions to withhold or withdraw LST other than CPR from a patient in a nursing home who is neither terminally ill nor permanently unconscious;
- ✧ Surrogate decisions to withhold or withdraw ANH from a patient in a hospital who is neither terminally ill nor permanently unconscious if the attending physician objects;
- ✧ Emancipated minor decisions to withhold or withdraw LST without the consent of parent or guardian.



Education and Training for Ethics Committees



- Requirements of new laws – overall, specific to ethics committees
- Written policies and procedures
- Paradigm shift
- Relational decision making
- Conflict negotiation and resolution
- Interdisciplinary process



Communication

Conclusions and Next Steps



- Nationally the field of end of life care is embracing a new paradigm, less formalistic, more process oriented.
- New law and regulation has created a “teachable moment” in New York
 - Implementation and institutional policy development can be more than pro forma
 - Ethics committees will need new education and professional development opportunities
 - Institutions need to find better ways to counsel and support health care agents and surrogates in the wake of FHCDA
- We have a significant opportunity to move in the direction of improved advance care planning and continuity of care for patients near the end of life
 - Develop protocols and tools for appropriate documentation and transfer
 - Ensure appropriate care planning, case management, and use of palliative care consultation
 - Facilitate ethically competent communication with and among family members
 - Facilitate ethically competent communication within the unit and among the health care team



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