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MEDICAL ETHICS COMMITTEES IN COMMUNITY HOSPITALS: WHY and HOW?

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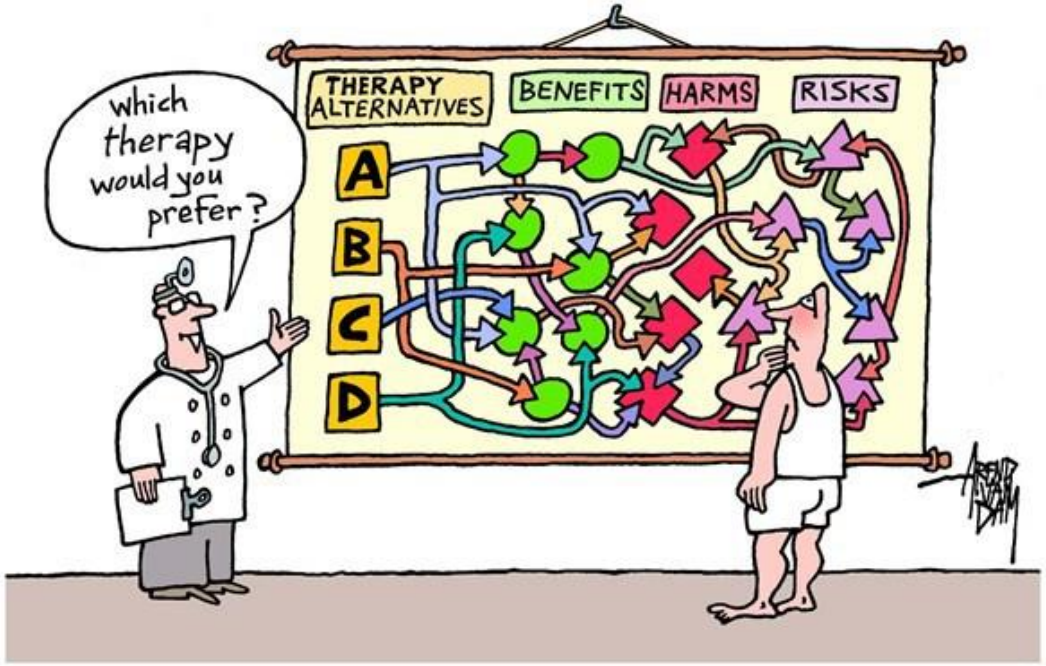
Tricky Informed Consent Issues



informed consent

"Who's on First?"

- Patient has been in an apparent persistent vegetative state for a week.
- Has a temporary feeding tube in place.
- Medical team considers her condition terminal, but is reluctant to document a finding of persistent vegetative state or of a terminal condition.
- Family is considering withdrawal of feeding tube.

"Who's on First?"

- If a feeding tube is to remain in place, a more permanent feeding tube should replace the temporary one soon.
- A hospital nurse thinks it would be "murder" to remove the patient's temporary feeding tube and tells the family so.
- Patient has no advanced directive.
- Patient's son wants to think about it for a week.

Agenda

1. Nebraska Informed Consent
2. Consent by Minors
3. Advance Directives
4. Nebraska Health Care Surrogacy Act
5. Nebraska Rights of the Terminally Ill Act
6. Staff Training Opportunities
7. Ethics Committees
8. Bio-Ethicist Resources vs. Legal Advice

Short Refresher on the Basics

Common Law

- Common law rule across states is that a patient has a right to accept or refuse treatment, therefore, the patient must consent to treatment or he or she may be entitled to recover for battery.

Rationale

- The informed consent doctrine is based on individual autonomy.
- "Although the procedure be skillfully performed, the doctor may nevertheless be liable for an adverse consequence about which the patient was not adequately informed." *Eccleston v. Chait*, 492 N.W. 2d 860 (Neb. 1992).
- The right to informed consent is enforced through civil lawsuits (in tort) under theories of battery or negligence.

Nebraska Statute

- The Nebraska informed consent statute provides:
  - "Informed consent shall mean consent to a procedure **based on information which would ordinarily be provided to the patient under like circumstances by health care providers engaged in a similar practice in the locality or in similar localities**. Failure to obtain informed consent shall include failure to obtain any express or implied consent for any operation, treatment, or procedure in a case in which a reasonably prudent health care provider in the community or similar communities would have obtained an express or implied consent for such operation, treatment, or procedure under similar circumstances."

    Neb. Rev. Stat. § 44-2816

Elements of Informed Consent

1. Physician/practitioner disclosure of material facts
2. Discussion with patient, including answering questions
3. Agreement by patient with capacity to make health care decision; or legally authorized representative
4. Documentation of informed consent, typically using a consent form supported by practitioner's office documentation

Hospital's Role in Informed Consent

In 1997, the Nebraska Supreme Court held "[a] hospital has no independent duty to obtain a patient's informed consent to a surgical procedure to be performed by a physician who is not an employee of the hospital; such duty lies exclusively with the treating physician."

Common Exceptions to Informed Consent Requirement

1. Emergencies/Implied Consent Doctrine
2. Continuing consent ("series" patient)
3. Routine care – when consent to routine care has been given and the treatment or procedure is part of routine care, e.g., vaccinations, blood draws

Capacity to Consent, In General

1. Minors – In Nebraska, unmarried persons under the age of 19 are incompetent to give informed consent unless emancipated or there is a statutory exception. In Iowa, the age of majority is 18 years.
2. Adults – Conscious adults are presumed to be competent, even those under EPC or Civil Commitment Orders.

"Parental" Relationships with Minors

- Natural parents are guardians of their children unless disqualified by court order, e.g., terminating parental rights (Neb. Rev. Stat. § 30-2608(1))
- Divorced/unmarried parents (Neb. Rev. Stat. § 42-381)
  - Divorcing parents must create a "parenting plan" to meet the needs of the child and delineating parental roles and responsibilities; both parents are presumed to have authority to consent to treatment unless stated otherwise. (Nev. Rev. Stat. § 43-2929(4)
- Step-Parents. Unless the step-parent has adopted the minor, step-parents do not have any right to give informed consent to treatment or to access the records on behalf of step-children
- Foster Parents generally do not have authority to consent to the minor's treatment. State caseworkers do.

Consent by Minors

- In a few instances, unemancipated minors are authorized by state law to consent to their own medical treatment, often with limitations.
- Nebraska Statutes
  - Sexually-transmitted diseases (Neb. Rev. Stat. § 71-504)
  - Blood alcohol testing (Neb. Rev. Stat. § 60-6,211.02)
  - HIV testing (Neb. Rev. Stat. § 71-531(1)(a)) AMENDED
  - Sexual assault collection of evidence (Neb. Rev. Stat. § 29-4306)

About Emancipated Minors

- By Statute
  - Neb. Rev. Stat. § 43-2101: persons under 19 may be emancipated by marriage, except that, pursuant to Nev. Rev. Stat. § 43-289, "[t]he marriage of any juvenile committed to a state institution under the age of 19 years shall not make such juvenile of the age of majority."
- Common Law
  - In Nebraska, the common law of emancipation appears in *Wulff v. Wulff*, 500 N.W.2d 845 (Neb. 1993)

Legal Guardianships

- Usually appointed by a court
- May be for adult or minor
- Parents may appoint a legal guardianship during an absence or semi-permanently, subject to revocation
- Incapacity a prerequisite finding for adult guardianships

Nebraska Office of Public Guardian

- The Office of Public Guardian is designed to serve as the guardian or conservator for an individual when no other alternative is available.
- In addition to providing a last resort for guardians or conservators when no family member or other individual is available, the Office of Public Guardian provides education, training and support for volunteer and family guardians and conservators, and recruits individuals to serve as guardians and conservators for Nebraska's vulnerable individuals.
- The Office of Public Guardian is guided by the Advisory Council on Public Guardianship.
- Work began on January 1, 2015, to develop the processes, guidelines, plans and personnel policies to implement the Public Guardianship Act.

Rights of the Terminally Ill Act

- Purpose is to:
  - recognize protected liberty interest for people to direct their medical treatment
  - Protect state's interests in preserving life, preventing homicide and suicide, protecting dependent third parties and maintaining integrity of the medical profession.

Rights of the Terminally Ill Act

- Act comes into play only for patients who have a Declaration, as defined.
- Attending physician determines that patient is in a terminal condition or a persistent vegetative state and records the diagnosis, determination and the existence of the Declaration in the medical record.
- Patient makes own decisions as long as able to do so.

Declaration or "Living Will"

- Signed document expressing patient's preference to have Life Sustaining Treatment initiated, continued, withheld or withdrawn in the event patient has a Terminal Condition or is in a Persistent Vegetative State and is unable to participate in decisions regarding care.
- Declaration may be carried out by a physician whether or not a Power of Attorney for Health Care has been signed, appointing an Attorney in Fact.

Declaration or "Living Will"

- Physician may rely on a Declaration only after documenting:
  - Patient has Terminal Condition or is in Persistent Vegetative State; and
  - Patient cannot make decisions re life-sustaining treatment; and
  - Physician has notified a reasonably available member of patient's family or a guardian of diagnosis and of intent to act upon the Declaration.
- Life-Sustaining Treatment cannot be withheld or withdrawn from a known pregnant patient if the fetus could survive to live birth with continued life-sustaining treatment.

Timing of Ethics Consult Can Be Important

- Consent is generally required to put life-sustaining treatment in place.
  - That means it can be refused.
- Removal of life-sustaining treatment typically requires surrogate decision-making.
  - Removal is very trying emotionally.

Power of Attorney for Health Care

- Principal, while competent, designates attorney-in-fact to act on principal's behalf when principal is incapable
- Activated upon the principal's incapability, as determined by a physician
  - Incapable means lacks ability to understand or appreciate nature and consequences of a proposed health care decision, including the benefits, risks, and alternatives; or lacks ability to communicate in any manner.
  - Reliance upon a PAHC, in good faith, protects the provider and hospital from liability if the PAHC was not current, was revoked, signed in a different state, etc.

Nebraska Health Care Surrogacy Act

- When an adult with no advance directive is determined to be incapable, the primary care provider may rely upon a surrogate.
- Surrogate should be guided by patient's prior statements re health care treatment.
- Incapable means lacks ability to understand or appreciate nature and consequences of a proposed health care decision, including the benefits, risks, and alternatives; or lacks ability to communicate in any manner.

Nebraska Health Care Surrogacy Act

- Court-appointed guardian
- Individual identified by patient as surrogate, to attending physician
- Spouse, if no divorce pending
- Adult child
- Parent
- Adult sibling
- Person who has demonstrated special care and concern for the patient, is familiar with patient's values and is reasonably available.

Nebraska Health Care Surrogacy Act

- A potential surrogate may decline to serve.
- Primary care provider may use discretion to pass on a potential surrogate who was abusive or if there is evidence he/she would not act in best interests of patient.
- Statute addresses resolution of dispute among >1 person in same priority class of potential surrogates.
- Primary care provider may also seek assistance of other providers or the ethics committee or ethics consultation process of the facility.

Nebraska Health Care Surrogacy Act

- If no surrogate available, primary care provider may take actions consistent with the Act the provider determines are appropriate, in accordance with the patient's personal values, if known, and moral and religious beliefs, if known, and to be in the best interests of the patient.
- A patient may disqualify a potential surrogate from serving by a signed and dated writing or by personally informing the primary care provider and a witness of the disqualification. This should be documented in the medical record.

Persistent Vegetative State

AMA Definition

- No evidence of:
  - awareness of self or environment; no interaction with others.
  - sustained, reproducible, purposeful or voluntary behavioral responses to visual, auditory, tactile or noxious stimuli.
  - language comprehension or expression.
- Return of sleep-wake cycles, arousal, even smiling, frowning, yawning.
- Sufficient hypothalamic and brainstem autonomic functions to survive if given medical or nursing care
- Bowel and bladder incontinence
- Variably preserved cranial nerve and spinal reflexes
- Diagnosis withheld until at least one month after loss of consciousness

Nebraska law definition

- Medical condition that, to a reasonable degree of medical certainty as determined in accordance with then current accepted medical standards, is characterized by a total and irreversible loss of consciousness and capacity for cognitive interaction with the environment and no reasonable hope of improvement

Legal, Clinical and Religious Standards

- Physicians may feel compelled to adhere to clinical standards in addition to legal standards.
  - They might differ.
- Confirm with physician that his/her clinical standards are met before relying on legal application.
- Catholic hospitals in particular have religious directives re preservation of life.

Religious Directives

- US Conference of Catholic Bishops: Ethical and Religious Directives for Catholic Health Care Services
- Care for the Beginning of Life: Catholic health care ministry witnesses to the sanctity of life "from the moment of conception until death."
- Care for the Seriously Ill or Dying: We have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome.

Staff Training Opportunities

- Train staff regularly and in advance re:
  - Nebraska law on informed consent
  - Hospital policy on informed consent
  - Advanced directives
  - Surrogate decision making
  - Withdrawal of life sustaining treatment
  - Considerations/thorough discussions before life sustaining treatments begin.
- Direct staff not to share personal views with patients and families.

Medical Staff Organizational Documents

- Many MS organizational documents do not address:
  - Determination of incapacity
  - Determination of terminal condition
  - Determination of persistent vegetative state
  - Surrogate decision making
  - Withdrawal of life sustaining treatment.
- Inclusion of these topics in the MS Rules and Regulations provides a roadmap for medical staff members.

Ethics Committees

- How are they set up?
- Who are the members?
- Is there training?
- Do they have bylaws or guidelines?
- What kind of situations lead to a meeting?
- Do they meet only when the situation arises?

Steps to Start an Ethics Committee

- Support of administrative and clinical leadership is key for an effective ethics committee.
- Needs assessment:
  - Do clinical and administrative staff encounter ethics issues or conflicts?
  - Do staff ever need to discuss an ethics situation with a competent resource?
  - Is there a need for education throughout the hospital?
  - Would an in-house resource be useful to staff and patients in addressing ethics challenges?

Steps to Start an Ethics Committee

- Leadership decision to create an EC.
- Identify EC leader.
  - Respected throughout the organization.
  - Committed to the EC's mission.
  - Have available time to perform committee functions.
  - Basic level of knowledge and skills in heath care ethics.
- Identify EC members – Multidisciplinary.
  - Physicians, advanced practice providers, social workers, nurses, risk managers, administrators, clergy and other community members.
- Draft EC purpose and activities documents.
  - Some hospitals use bylaws or charter statements plus policy and procedure documents.
  - Other hospitals have more informal ways to define the EC's role in the hospital.

Steps to Start an Ethics Committee

- Seek leadership approval of the purpose and activities.
  - ECs might report to the Board of Directors, Hospital Administration or the Medical Staff.
- Market the EC's purpose and activities throughout the hospital to encourage consultation.
- Develop and pursue an EC self-education program.
  - Educational component to each EC meeting.
  - Rotate responsibility for education among EC members.
- Implement EC activities.
- Periodically review the EC's activities.
  - Use surveys, focus groups or seek feedback in informal settings.
  - Make changes to ensure EC is providing a useful service.

Traditional Model for EC Structure

- 3 to 5 interdisciplinary members.
  - Larger committees are difficult to convene on short notice.
- Full committee engages in review of patient dilemma and advisory process.
- Education.
- Review policies to assure EC approach is appropriate; does not create conflict or confusion at organizational or patient care level.

Alternative Models for EC Structure

- Divide traditional EC into sub-committees or teams for different ethical areas.
- Designate an ethics expert.
- Link EC or administration with an ethicist from a CAH network or academic center.
- Form a multi-facility EC.

EC Meetings

- Requests for consultation initiated by:
  - patient, family, attending physician, other health care practitioners or any person with a significant relationship with patient.
- Consultation meetings scheduled on an as-needed basis in response to a request.
- Other meetings scheduled on a regular basis to provide education, review hospital policies and procedures and review EC activities.

Ethics Committees – General Challenges

- Viewed as primarily educational;
- Commonly underutilized resource;
- Committee takes time to convene -- bioethical issues are immediate;
- Members might need training in bioethics;
- Staff might fear questioning care on ethical issues as a challenge to hierarchy, and fear retaliation.

Ethics Committees – Smaller Community Hospital Challenges

- Risk of familiarity among EC members, patients and staff;
- Conflicts of interest could arise between EC members and patient/family;
- Confidentiality is a challenge if EC members are local and know the patient involved;
- Difficulty staffing EC due to small personnel pool;
- Lack of effective training materials focused on rural ethics issues;
- Physician viewed as the authority figure, and generally able to finesse ethical issues alone.

Role of Legal Advice

- Assist hospital clients to understand the legal standards and requirements based on applicable law;
- Interpret hospital policy and procedures;
- Navigate any inconsistency between legal and clinical standards and/or hospital policies and procedures;
- Assist physicians, nurses and administration to apply legal standards to the patient's condition and family questions and decisions.

Role of Ethicist: Ethics Begins Where the Law Ends

- Ethical norms may be derived from:
  - Law;
  - Hospital policies/practices;
  - Professional standards of care;
  - Fiduciary obligations;
  - Community standards;
  - Religious tenants.
- Where two interests are opposed, but both are legally permissible, bioethicist can assist to weigh options.

Questions?

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