

DrinkerBiddle

**Focus 2014: The Art and Science of End of Life Care**

Department of Health Services  
November 19, 2014

---

**“Ethical and Legal Issues at the End of Life”**

Robyn S. Shapiro, J.D.

---

---

---

---

---

---

---

---

---

---

DrinkerBiddle

- > Introduction
- > Ethical Principles/Guidelines, Paradigm for Application
- > Legal Issues at the End of Life
  - Informed Consent/Informed Refusal
  - Decision Making Capacity
  - Decision Making on Behalf of Incapacitated Patients
    - Case Law
    - Advance Directives
    - Guardianship
  - Physician Assisted Suicide and Euthanasia
- > Challenges
- > Tools and Resources – Ethics Committees, Ideas for Future Legislative Initiatives

2

---

---

---

---

---

---

---

---

---

---

DrinkerBiddle

Introduction

- > What is “bioethics” in the health care setting?
  - Identification, analysis, resolution of ethical issues in patient care.

3

---

---

---

---

---

---

---

---

---

---

- > How is "ethics" different from "morality"?
  - Moral choices rest on values or beliefs that cannot be proved, are simply accepted. Morality refers to conduct that conforms to accepted customs or conventions.
  - Ethics denotes deliberation and arguments to justify particular actions. It focuses on reasons why an activity is considered right or wrong and asks people to justify their positions by rational arguments.

4

---

---

---

---

---

---

---

---

---

---

- > How is "ethics" different from "law"?
  - On many issues, law reflects an ethical consensus in society, but law often cannot provide definitive answers for ethical dilemmas
    - Law usually sets only a minimally acceptable standard of conduct (indicating what acts are so wrong that actor will be held legally liable); ethics focuses on the right or best decision under the circumstances
    - Law often does not provide clear guidance on salient issues
    - Law and ethics may conflict

5

---

---

---

---

---

---

---

---

---

---

- > History of Bioethics
  - "They Decide Who Lives, Who Dies," *Life*, November 9, 1962  
(Seattle lay committee selects chronic hemodialysis recipients)
    - Non-M.D.s charged with fairly selecting candidates for medical treatments

6

---

---

---

---

---

---

---

---

---

---

- "Ethics and Clinical Research," Henry Beecher, *NEng J Med* (June 16, 1966), leading to National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974-1978)
  - Recognition that research needs to not only advance science but protect rights and welfare of subjects;
  - Involvement of non-M.D.s in doing so;
  - Evolution of concepts of patient autonomy, informed and proxy consent, equilibration of risks and benefits.

7

---

---

---

---

---

---

---

---

- Christian Barnard performs heart transplant 1967;
  - Harvard Medical School committee proposes "brain death", with input from philosophers as to whether calling someone "dead" is a matter of biological fact or a normative philosophical judgment about when to treat a person as dead.

8

---

---

---

---

---

---

---

---

- Karen Quinlan's parents request withdrawal of life support 1975;
  - New Jersey Supreme Court recognizes dilemmas created by life-support technology (March 31, 1976);
  - Debate about ending life support goes public;
  - Ethics committees emerge.
- Baby Doe
- Genetics
- ...and more

9

---

---

---

---

---

---

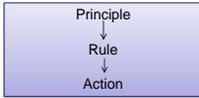
---

---

Ethical Principles/Guidelines

- > Autonomy/Respect for Persons
- > Beneficence/Benefit the Patient
- > Nonmaleficence/Do No Harm
- > Justice/Allocate Resources Justly

Application:



10

---

---

---

---

---

---

---

---

---

---

Legal Issues at the End of Life

Case Study #1: Henry

- > 69 year old retiree, previously bank president, married, 3 adult children
- > Recent trouble with gait, wrists
- > Early ALS diagnosis
- > Conference with care team and wife; wishes no ventilatory support in future; wife disagrees

11

---

---

---

---

---

---

---

---

---

---

- > Informed Consent/Informed Refusal
  - Underlying principle: right to say "yes" or "no"
  - Ethical basis: autonomy
  - Legal basis: tort law right to bodily integrity, constitutional liberty interests
  - Elements of informed consent discussion:
    - Nature, risks, benefits, alternatives, no treatment

12

---

---

---

---

---

---

---

---

---

---

### Case Study #2: Anna

- > 79 year old widow, lives alone, 2 daughters out of state, caretaker help 3 days/week, history of diabetes
- > Recent confusion; diagnosis - probable early Alzheimer's
- > Now needs below-knee amputation; refuses

13

---

---

---

---

---

---

---

---

---

---

### > Decision Making Capacity

- Elements:
  - Understand the information
  - Process it in accordance with own value history
  - Make and communicate choice
- WI Statutory Definition: Activating HCPOA
  - 155.01(8) "Incapacity means the inability to receive and evaluate information effectively or to communicate decisions to such an extent that the individual lacks the capacity to manage his or her health care decisions."

14

---

---

---

---

---

---

---

---

---

---

- vs "Incompetence" and appointment of guardian of person (17 and 9 months)
  - Court must find by clear and convincing evidence that, because of impairment, individual unable effectively to receive and evaluate information or make or communicate decisions to such extent that individual unable to meet essential requirements for his/her physical health and safety – and needs can't be met effectively and less restrictively through training, education, support services. (Determination can't be based on old age, eccentricity, poor judgment, physical disability.)

15

---

---

---

---

---

---

---

---

---

---

### Case Study #3: Anna

- > Loses consciousness at home, revived by caretaker, taken to hospital
- > On ventilator, daughter in Cal. wishes withdrawal

16

---

---

---

---

---

---

---

---

### > Decision Making on Behalf of Incapacitated Patient

- Underlying principles:
  - Rights not lost (Quinlan, Cruzan, LW)
  - Withholding/withdrawing under appropriate circumstances ≠ suicide or homicide
  - Artificial nutrition and hydration = medical treatment
- Issues:
  - Who speaks for incapacitated patient?
  - On basis of what?

17

---

---

---

---

---

---

---

---

- Response to Issues: Case Law in WI
  - In re L.W. 167 Wis. 2d 53, 482 N.W. 2d 60 (1992)  
Facts: 79 year old chronic schizophrenic, in and out of group homes, corporate guardian, cardiac arrest, pvs, ventilator dependent  
Holding: Guardian has authority to consent to withdrawal of LST, without prior court approval, if withdrawal determined to be in ward's best interests.  
Factors to consider: degree of humiliation, dependence, loss of dignity resulting from condition and treatment, life expectancy, prognosis with and without treatment, options.

18

---

---

---

---

---

---

---

---

- In re Edna M.F., 210 Wis. 2d 558, 563 N.W. 2d 485 (1997)  
Facts: 71 year old in late stage Alzheimer's dementia, previously accomplished journalist, active community member, guardian = sister and best friend, close to pvs (but exhibited some minimal response), past statement regarding treatment preferences  
Holding: When incompetent individual is not in pvs, "as a matter of law" it is not in her best interests to withdraw LST unless is clear evidence that this would be her desire.

---

---

---

---

---

---

---

---

---

---

- Advance Directives
  - Wisconsin Statutes Chapter 154 – Living Will
    - Specifies that adults may execute "Declaration to Physicians" authorizing withholding, withdrawal of LSPs or feeding tubes when person in terminal condition or pvs
    - Includes form
    - Requires MD who can't comply to make good faith attempt to transfer patient
    - Extends immunity
    - Affords reciprocity

---

---

---

---

---

---

---

---

---

---

- Do Not Resuscitate –
  - Describes DNR bracelet, available to "qualified patient" (i.e., adult who has terminal condition, or condition such that resuscitation would cause significant physical pain or harm that outweighs possibility of successful resuscitation for indefinite period of time) who has DNR order
  - Provides that attending may issue DNR order if patient is "qualified", not pregnant, has asked (or guardian or health care agent has asked), and consents (or guardian or health care agent consents) after being provided with information
  - Protects emergency medical technicians, first responders, ER personnel who do not attempt CPR

---

---

---

---

---

---

---

---

---

---

- Wisconsin Statutes Chapter 155 – Power of Attorney for Health Care
  - Specifies that adults may execute POAHC, which is activated upon finding of incapacity by 2 physicians, or physician and psychologist
  - Includes form
  - Specifies powers of agent, including authority to consent to withholding/withdrawal of feeding tube if document so authorizes
  - Requires agent to act consistently with principal's desires
  - Extends immunity
  - Affords reciprocity

---

---

---

---

---

---

---

---

- Guardianship
  - Findings Necessary to Appoint Guardian of Person
    - Because of an impairment, individual is unable effectively to receive and evaluate information or to make or communicate decisions to such an extent that the individual is unable to meet the essential requirements for his/her physical health and safety.

---

---

---

---

---

---

---

---

- Definitions
  - "Impairment" means a developmental disability, serious and persistent mental illness, degenerative brain disorder, or other like incapacities.
  - "Least Restrictive" means that which places the least possible restriction on personal liberty and the exercise of rights and that which promotes the greatest possible integration of an individual into his or her community that is consistent with meeting his/her essential requirements for health, safety, habilitation, treatment, and recovery and protecting him/her from abuse, exploitation, and neglect.

---

---

---

---

---

---

---

---

- Rights of Wards
  - Three categories:
    - › Rights that may not be removed and are exercised by the ward without guardian consent
    - › Rights that may be removed but may not be exercised by guardian
    - › Rights that may be removed and may be exercised by guardian

---

---

---

---

---

---

---

---

---

---

- Rights that may never be removed and are exercised by the ward without guardian consent
  - To have access to and communicate privately with the court and governmental representatives, including the right to have input into plans for support services, the right to initiate grievances, and the right to participate in administrative hearings and court proceedings
  - To have access to, communicate privately with, and retain legal counsel
  - To have access to and communicate privately with representatives of the protection and advocacy agency and board on aging and long-term care

---

---

---

---

---

---

---

---

---

---

- Rights that may never be removed and are exercised by the ward without guardian consent (cont'd)
  - To protest a residential placement
  - To review the need for guardianship and/or protective placement or services
  - To give or withhold consent reserved to the individual under chapter 51 (Mental Health Act)
  - To exercise constitutional rights such as the right to free speech, freedom of association, and the free exercise of religious expression

---

---

---

---

---

---

---

---

---

---



- Rights that may be removed but may be exercised by guardian (cont'd)
  - To give informed consent to release of confidential records other than court, treatment, and patient health care records
  - To make decisions regarding mobility and travel
  - To choose providers of medical, social, and supported living services
  - To make decisions regarding educational and vocational placement and support services of employment

---

---

---

---

---

---

---

---

---

---

- Rights that may be removed but may be exercised by guardian (cont'd)
  - To make decisions regarding initiating a petition to terminate a marriage
  - To receive all notices on behalf of the ward
  - To act in all proceedings as an advocate of the ward
  - To apply for protective placement or commitment
  - To have custody of the ward, if an adult
  - Any other power the court specifically identifies

---

---

---

---

---

---

---

---

---

---

- Guardian's duty: advocate for ward's best interests; exhibit the utmost degree of trustworthiness, loyalty and fidelity in relation to ward; exercise degree of care, diligence and good faith when acting on behalf of ward that ordinarily prudent person exercises in his/her own affairs.
  - Because guardianship is created by court, decisions by guardian always subject to court review and supervision.

---

---

---

---

---

---

---

---

---

---

Case Study #4, Anna cont.

- > Daughter calls MD, says her mother would not want to live this way, asks him to "take care of it"

34

---

---

---

---

---

---

---

---

> Physician Assisted Suicide and Euthanasia

- No constitutional right; states may develop laws, issue judicial decisions
- Washington, Oregon, Montana, Vermont
- Oregon experience (1998-2010)
  - 525 deaths (0.3% of deaths)
  - Reasons
    - Loss of autonomy (91%)
    - Loss of activities (88%)
    - Loss of dignity (82%)
    - Loss of bodily functions (56%)
    - Burden to others (35%)

[Note: not pain, finances]

- > Euthanasia: Illegal throughout U.S.

35

---

---

---

---

---

---

---

---

Challenges

- > Guardianship: time consuming, expensive
- > Living Will pertinent to limited circumstances, does not specify decision maker
- > POAHC may not specify patient's treatment preferences
- > Documents may be too confusing, intimidating to patients
- > Yet – without clear guidance to loved ones and caregivers from now-incapacitated patient (in advance directive or otherwise), difficult for surrogates to make decision, less likely that patient's preferences will be honored (see Mack JW, Weeks JC, Wright AA, Black SD, Peregerson HG. *End of Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent with Preferences.* J Clin Oncol 2010;1203-1208, finding that terminally ill patients who talked with physicians about preferences were 3.5 x more likely to have preferences honored).

36

---

---

---

---

---

---

---

---

### Tools and Resources

#### > Ethics Committees

- History
  - First described in literature by Karen Teel, MD, neonatologist, who described Baylor's ethics committee (1975)
  - First described judicially In re Quinlan, 70 N.J.20, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976)
  - President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research: Deciding to Forego Life-Sustaining Treatment (1983) – strongly encouraged creation of ethics committees to aid decision-making:

37

---

---

---

---

---

---

---

---

---

---

- Care providers should "explore and evaluate various... administrative arrangements for review and consultation, such as 'ethics committees,' particularly for decisions that have life and death consequences."
- Ethics committees "more rapid and sensitive than judicial review."

38

---

---

---

---

---

---

---

---

---

---

- Some courts have recognized that consulting with ethics committee may relieve providers from seeking judicial approval for actions, e.g., In re Guardianship of Browning, 543 So. 2d 258 (Fla App. 2d Dist. 1989); In re Conservatorship of Torres, 357 N.W. 2d 332 (Minn. 1984)
- Ethics committees now present in virtually all hospitals – Joint Commission requires mechanism for resolving ethical issues

39

---

---

---

---

---

---

---

---

---

---

DrinkerBiddle

- Functions

- Education – e.g.,
  - Ethics rounds
  - Ethics library
  - Ethics newsletter
  - Ethics website
  - Community outreach ethics programs

40

---

---

---

---

---

---

---

---

---

---

DrinkerBiddle

- Policy Development – e.g.,
  - Do Not Resuscitate
  - Refusal of treatments
  - Confidentiality
  - Ethics consult process
  - Advance directives

41

---

---

---

---

---

---

---

---

---

---

DrinkerBiddle

- Case Consultation – help identify, analyze and resolve ethical problems in patient care, e.g., when decisions involve:
  - Significant ethical ambiguity
  - Disagreements among care providers or between providers and patient/family
  - Withholding or withdrawing life sustaining treatment

42

---

---

---

---

---

---

---

---

---

---

### Mock Ethics Committee Case Consultation

Consult #1: Travis Staples is 32 years old and has been married to his wife, Paula, a little over a year. One evening, Travis is in a severe one-car accident while out of state on a work-related trip and is left not breathing for an extended period of time. The paramedics are called, who transport Travis to the Hospital, where he is ultimately resuscitated and placed on a ventilator. Travis remains comatose for over three months. While initially fed by means of a nasogastric feeding tube, he eventually receives a percutaneous endoscopic gastrostomy (PEG) feeding tube that is inserted through his abdominal wall. Travis is ultimately removed from the ventilator and is able to resume breathing on his own. Upon emerging from the coma, Travis, despite having his eyes open and moving, is diagnosed by two different physicians as suffering from a persistent vegetative state, resulting from brain injury caused by the extended period of time during which Travis was without oxygen prior to the arrival of

---

---

---

---

---

---

---

---

---

---

---

---

### Mock Ethics Committee Case Consultation, cont.

the paramedics. Both physicians are also of the opinion that Travis' likelihood of recovery is poor but that with good nursing care Travis could continue to live in his current state for upwards of another 30 years. Travis does not have any advance directives in place. Accordingly, Paula petitions the court to be appointed as Travis' guardian. After 5 years, Travis' condition has not improved. Based on Paula's claims that Travis had previously told her that he did not want to remain on life support if there was no likelihood of improvement, Paula informs the Hospital that she would like to have Travis' feeding tube removed. Travis' parents disagree and argue that Travis is conscious due to his open eyes and what they view as Travis' attempts to respond to their interaction with him through making sounds, which consist of moans and sighs. What should be done?

---

---

---

---

---

---

---

---

---

---

---

---

### Mock Ethics Committee Case Consultation, cont.

Consult #2. Mr. Wilson, a brilliant academic, appointed his wife health care agent with instructions not to provide artificial nutrition or hydration if he became severely demented. Mr. Wilson is now demented but maintains a pleasant affect, though he cannot converse and no longer recognizes family. He is now unable to feed himself or take food by mouth. The Facility proposes to place a PEG tube to provide nutrition and hydration. His wife refuses to allow this; the Facility Administrator believes that Mr. Wilson is no longer the person who executed the advance directive but a "pleasantly demented individual" who may be enjoying his life. What should be done?

---

---

---

---

---

---

---

---

---

---

---

---

### Consider Legislative Options

- POLST (?)
- "Right to Know End-of-Life Options Act" – e.g., in Cal. Stats. Chapter 683 (2008)
  - Could help spur discussions between physicians and patients (See Health Affairs, 2003; 22:190-7: 31% U.S. physicians withheld information about treatment options that they did not think would be covered by insurance; J Clinical Oncology 2008: only 16% oncologists discussed patients' terminal prognosis.)
  - Would require that if provider makes terminal illness diagnosis, upon patient's request, must provide information and counseling about end-of-life options, including right to refuse unwanted treatment, or provide referral or transfer

---

---

---

---

---

---

---

---

---

---

- Palliative Care Info Act – NY (NY S Public Health Law Sec. 2997-C)
  - Requires health care practitioner to offer to provide palliative care information and end of life options to patient diagnosed with terminal illness or condition

---

---

---

---

---

---

---

---

---

---