Clinical Ethics Consultation: Standards, Structures, and Strategies

Becky Benson, MD, PhD
Director, Ethics Consult Service
Medical Director, Pediatric Pain & Palliative Care Program
Clinical Associate Professor, Department of Pediatrics
Division of General Pediatrics and Adolescent Medicine
University of Iowa Carver College of Medicine

CHANGING MEDICINE.
CHANGING LIVES.®

1

Disclosures

- I have nothing to disclose.

UNIVERSITY OF IOWA HEALTH CARE 2

2

Objectives

- Identify key events and issues that have led to the emergence of contemporary clinical ethics consultation.
- Describe the goals and scope of clinical ethics consultation and distinguish it from the roles of an ethics committee or policy review committee.
- Discuss advantages and disadvantages of individual, small team, and committee models for providing ethics consultation.

UNIVERSITY OF IOWA HEALTH CARE 3

3

Key Events and Issues Leading to Emergence of Contemporary Clinical Ethics Consultation

4

Early Days of Medical Ethics

- 1803: *Medical Ethics* (Dr. Thomas Percival)
  - Percival coined the term "medical ethics"
  - Formed foundation for modern codes of ethics (i.e., AMA Code of Ethics)
- 1949: "Medico-moral Committees"
  - Purpose: to discuss and uphold Catholic values in healthcare delivery
- 1954: *Morals and Medicine* (Joseph Fletcher, theologian)
  - Examined problems of conscience raised by new advances in medicine (i.e., artificial insemination, euthanasia)

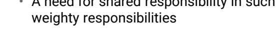
UNIVERSITY OF IOWA HEALTH CARE 5

Patuzzo S, Goracci G, Cilibert R. *Acta Biomed.* 2018.
Tapper EB. *Proc (Bayl Univ Med Cent).* 2013.

5

Outpatient Renal Dialysis and the "God Squad"

- 1960: Scribner's arteriovenous shunt enabled outpatient renal dialysis
  - Raised concerns about fairness in rationing as demand quickly outweighed supply
  - Seattle Artificial Kidney Center created an "Admissions and Policy Committee," later coined the "God Squad"
  - 1962 *Life* article by Shana Alexander
    - "they [the "God-Squad"] decide who lives, who dies"
    - A need for shared responsibility in such weighty responsibilities



UNIVERSITY OF IOWA HEALTH CARE 6

Alexander S. *LIFE Magazine.* 1962; Jonsen AR. *J Law Med Ethics.* 2007; Tapper EB. *Proc (Bayl Univ Med Cent).* 2013.

6

Irreversible Coma as New Criterion for Death

- 1953: first ICU
- 1950s and 1960s: technological innovations in care of critically ill patients and advancements in organ transplantation
- 1968: Harvard committee provides a definition of "irreversible coma as a new criterion for death"
  - Confronted issues of organ supply and when it is appropriate to terminate life support to harvest organs

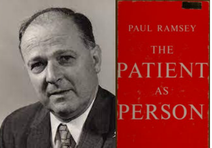
Fig. 1 The Ad Hoc Committee of the Harvard Medical School. Top: Henry Beecher, chairman (Anesthesiology). First row: Joseph Murray (transplant surgery), Raymond Adams (neurology), Robert Schwab (neurology) and William Curran (law). Second row: William Sweet (neurosurgery) Derek Denny-Brown (neurology). Jordi Folch-pi (biochemistry), John Merrill (transplant nephrology). Third row: Clifford Barger (physiology), Dana Farnsworth (public health,), Ralph Potter (social ethics), and Everett Mendelson (history). (Kindly provided by Harvard University and from personal files)

Harvard Medical School to Examine the Definition of Brain Death. *JAMA*. 1968; Kelly FE, Fong K, Hirsch N, Nolan JP. *Clin Med.* 2014; Nair-Collins M. *Perspect Biol Med.* 2022; Wijdicks EFM. *Neurocrit Care.* 2018

7

Bioethics as a Field

- 1970: *The Patient as a Person* (Paul Ramsey, theologian)
  - Provided intellectual foundation for field of bioethics
  - Addressed: who should receive scare and vital treatment; how we determine when life ends; what limits should be placed on care for the dying

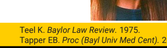


Tapper EB. *Proc (Bayl Univ Med Cent).* 2013.

8

The Physician's Dilemma

- 1975: *The Physician's Dilemma* (Dr. Karen Teel)
  - The physician "is charged with the responsibility of making ethical judgements which we are sometimes ill-equipped to make"
  - Suggested that all hospitals should "provide a regular forum for more input and dialogue in individual situations and to allow the responsibility of these judgments to be shared"
- 1976: Quinlan legal decision
  - New Jersey Supreme Court unanimously ruled that the right to privacy encompassed a person's right to forgo life-sustaining treatment
  - Judge Hughes cited Dr. Teel and urged hospitals to adopt her suggestion for ethics committees



Teel K. *Baylor Law Review.* 1975.
Tapper EB. *Proc (Bayl Univ Med Cent).* 2013.

9

Birth of Clinical Ethics Consultation

- 1970s: A small group of ethicists began offering consultations
  - Albert Jonsen, philosopher, likely first ethics consultant at bedside in early 1970s
- 1972: Dr. Mark Siegler created the new field of clinical ethics
  - "Focuses on issues that confront the physician in his daily interactions with patients"
- 1984: First ethics consultation in published record (Ruth Purtilo, professor of ethics and physical therapy)
  - Highlights the importance of the ethics consultant by pointing out, "…most cases in which a clinician can benefit from a sympathetic and skilled ethicist never reach the committee"

UNIVERSITY OF IOWA HEALTH CARE 10 Purtillo RB. *N Eng J Med*. 1984. Tapper EB. *Proc (Bayl Univ Med Cent)*. 2013.

10

Contemporary Clinical Ethics Consultation

- 1982: "Four Box Method" from *Clinical Ethics*
  - A case-based approach to ethical decision-making
  - Jonsen, Siegler, Winslade
- 1986: Society for Bioethics Consultation
  - Aimed to sponsor conferences, raise funds for training grants, and help organizations build training programs

MEDICAL INDICATIONS The Principles of Beneficence and Nonmaleficence	**PATIENT PREFERENCES** The Principle of Respect for Autonomy
1. What is the patient's medical problem? Is the problem acute? Chronic? Critical? Reversible? Emergent? Terminal? 2. What are the goals of treatment? 3. In what circumstances are medical treatments not indicated? 4. What are the probabilities of success of various treatment options? 5. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?	1. Has the patient been informed of benefits and risks, understood this information, and given consent? 2. Is the patient mentally capable and legally competent, and is there evidence of incapacity? 1. If mentally capable, what preferences about treatment is the patient stating? 2. If incapacitated, has the patient expressed prior preferences? 3. Who is the appropriate surrogate to make decisions for the incapacitated patient? 4. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
QUALITY OF LIFE The Principles of Beneficence, Nonmaleficence, and Respect for Autonomy	**CONTEXTUAL FEATURES** The Principles of Justice and Fairness
1. What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds? 2. On what grounds can anyone judge that some quality of life would be undesirable for a patient who cannot make or express such a judgment? 3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life? 4. What ethical issues arise concerning improving or enhancing a patient's quality of life? 5. Do quality-of-life assessments raise any questions regarding changes in treatment plans, such as forgoing life-sustaining treatment? 6. What are plans and rationale to forgo life-sustaining treatment? 7. What is the legal and ethical status of suicide?	1. Are there professional, interprofessional, or business interests that might create conflicts of interest in the clinical treatment of patients? 2. Are there parties other than clinicians and patients, such as family members, who have an interest in clinical decisions? 3. What are the limits imposed on patient confidentiality by the legitimate interests of third parties? 4. Are there financial factors that create conflicts of interest in clinical decisions? 5. Are there problems of allocation of scarce health resources that might affect clinical decisions? 6. Are there religious issues that might affect clinical decisions? 7. What are the legal issues that might affect clinical decisions? 8. Are there considerations of clinical research and education that might affect clinical decisions? 9. Are there issues of public health and safety that affect clinical decisions? 10. Are there conflicts of interest within institutions or organizations (e.g. hospitals) that may affect clinical decisions and patient welfare?

UNIVERSITY OF IOWA HEALTH CARE 11 Jonsen AR, Siegler M, Winslade WJ, eds. *Clinical Ethics*. 2022. Tapper EB. *Proc (Bayl Univ Med Cent)*. 2013.

11

Contemporary Clinical Ethics Consultation

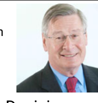
- By 1987: Clinical ethics consultation growing
  - A manual, a published record of experiences, journals, textbooks
- 1998: First edition of the ASBH's Core Competencies for Healthcare Ethics Consultation
- 1992: JCAHO required all approved hospitals to have a means of resolving ethical conflicts
- 2011: Most recent edition of the ASBH's Core Competencies for Healthcare Ethics Consultation

UNIVERSITY OF IOWA HEALTH CARE 12 Tapper EB. *Proc (Bayl Univ Med Cent)*. 2013.

12

The Health Care Dilemma

Sir Cyril Chantler
British pediatric nephrologist in practice from 1971 – 2001
Lancet 1999 article about delivery of healthcare



- Demand for healthcare is rising, and resources do not always keep up. Decisions are being made with or without our awareness.
- *"Medicine used to be simple, ineffective, and relatively safe. Now it is complex, effective, and potentially dangerous..."*
- *"We must recognise and encourage our patient's right to make fully informed decisions about available treatments and provide care and support, not just technically advanced interventions."*
- Patients need to know: What is wrong? Why? What can/should be done? Who should do it? What can I expect?
- Doctors need to think about: Efficacy, Effectiveness, Efficiency, Equity, and Economy

UNIVERSITY OF IOWA HEALTH CARE 13 Chantler C. *Lancet*. 1999.

13

Contemporary Clinical Ethics Consultation

- According to a nationwide survey of 600 US hospitals:
  - 97.1% had a clinical ethics consultation service in 2018
  - Median number of case consultations doubled between 2000 and 2018 in hospitals with bed size ≥400

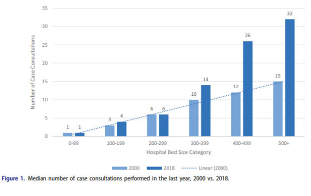


Figure 1. Median number of case consultations performed in the last year, 2000 vs. 2018.

UNIVERSITY OF IOWA HEALTH CARE 14 Fox E, Danis M, Tarzian AJ, Duke CC. *Am J Bioeth*. 2022.

14

Goals, Scope, and Distinguishing Characteristics of Clinical Ethics Consultation

15

Definition of Clinical Ethics Consultation

"A set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care."

ASBH Core Competencies Task Force. 2011, p. 2.

16

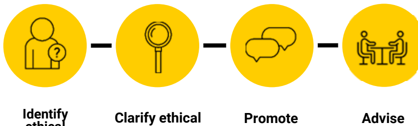
Goals of Clinical Ethics Consultation

- **Overall Goal**: improve health care quality through identification, analysis, and resolution of ethical questions/concerns
- **Other goals**:
  - Identify and analyze the nature of the value uncertainty or conflict
  - Facilitate resolution of conflicts in a respectful atmosphere with attention to the interests, rights, and responsibilities of all involved

ASBH Core Competencies Task Force. 2011, p. 3.

17

Goals of UIHC Ethics Consult Service



18

Scope of Questions Arising in Ethics Consultation

Core Competencies for Healthcare Ethics Consultation, 2nd edition. A Report of the American Society for Bioethics and Humanities

Table 1. Scope of Questions Arising in HCEC

CONTENT DOMAINS	EXAMPLES OF ETHICS QUESTIONS
Shared decision making with patients	What degree of intellectual disability makes a patient incapable of giving informed consent for a medical procedure?
	Who should be authorized to make decisions on behalf of a patient who lacks medical decision-making capacity?
Ethical practices in end-of-life care	Should cardiopulmonary (CPR) attempts be withheld without patient/surrogate consent?
	Is stopping enteral nutrition for a patient ethically justified?
Ethical practices at the beginning of life	Is comfort care alone an ethically appropriate option for an extremely low-birth-weight premature infant?
	Should a woman in full-term labor be allowed to refuse a recommended cesarean section?
Patient privacy and confidentiality	Should a woman be allowed to keep her son's HIV+ status secret from the child's father?
	Should a physician seek permission from a patient before using the patient's case for teaching purposes?
Professionalism in patient care	What gifts from pharmaceutical companies to healthcare professionals, if any, are ethically acceptable?
	When are overlapping professional/personal relationships inappropriate?
Ethical practices in resource allocation	How should intensive care unit (ICU) beds be triaged?
	Should disposable medical devices be sterilized and reused to save resources?
Ethical practices in business and management	How should healthcare services be advertised?
	What constitutes fair billing and coding practices?
Ethical practices in the everyday workplace	What should be done about a verbally abusive surgeon?
	When is it ethically justifiable for a nurse to refuse to implement an order he or she finds morally objectionable?

UNIVERSITY OF IOWA HEALTH CARE 19 ASBH Core Competencies Task Force. 2011, p. 5.

19

When to Request an Ethics Consult

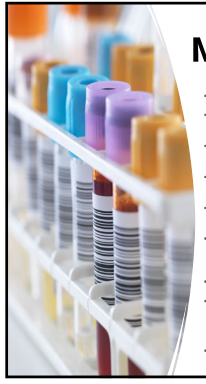
- To "talk through" important ethical dimensions of a patient's care
- A patient's care raises unusual, unprecedented, or very complex ethical issues
- Need help making an ethically significant decision
- Efforts by patient, family, and professional staff to resolve an ethical problem have reached an impasse
- There is serious ethical disagreement among health care professionals or within the professional-patient/family relationship about the course of treatment

UNIVERSITY OF IOWA HEALTH CARE 20

20

Case 1: Mr. and Mrs. G

21



Mr. G and Mrs. G

- 80-year-old with progressive vascular dementia admitted for blood in stools
- Treated for esophagitis but continues to have intermittent tarry stools and progressive weakness
- Past medical history: chronic kidney disease, atrial fibrillation no longer on anticoagulation, past stroke and vascular dementia, deconditioned
- On hospital day 2 he developed shortness of breath and increased oxygen requirement and was found to have pulmonary embolism and aspiration when eating
- Team has concerns that further workup or treatment is risky, burdensome, and that his life expectancy is days to weeks regardless of treatment
- Mr. G (when alone) says consistently that he wants to go home, feels he has had "a good life and it's ok if it's my time to go", and does not want further testing or intervention – but he has limited capacity due to dementia
- Mrs. G is the durable power for healthcare and main caregiver and is visiting every day
- When having goals of care discussions with them together in the room, she tells him he needs to "fight" to get better and wants extensive workup and treatment
- What is the ethical issue here?

22

Mr. G and Mrs. G

- 80 year old with progressive vascular dementia admitted for blood in stools
- Ethical issue?
  - Concern that surrogate decision-maker is not using substituted judgement (disagreeing with patient expressed preference) or even best interest standards (team not promoting further intervention due to risk/benefit ratio)
- What else do you want to know?
- Potential reasons for Mrs. G's response
  - Lack of understanding of medical situation?
  - Grief response?
  - Secondary gain?
- Resolution – initially Mr. G deferred to his wife. After another 1-2 days of processing, she decided to take him home with hospice support.

23

Most Common Ethical Issues at UIHC

In 2019

1. Best interests of patient
2. Surrogate decision making (identifying/obtaining or reliability of)
3. Goals of care (clarification of)
4. Decision making capacity in adults (assessment or absence of)
5. Refusal of a recommended treatment plan

In 2020

1. Surrogate decision making (identifying/obtaining or reliability of)
2. Best interests of patient
3. Potentially inappropriate treatment given patient's poor prognosis
4. Goals of care (clarification of)
5. Issues of justice

In 2021

1. Best interests of patient
2. Surrogate decision making (identifying/obtaining or reliability of)
3. Potentially inappropriate treatment given patient's poor prognosis
4. Decision making capacity in adults (assessment or absence of)
5. Goals of care (clarification of)

University of Iowa Health Care 24

24

Other Common Ethical Issues at UIHC

- Refusal of recommended treatment or plan
- Issues of justice
- Disagreement over treatment plan
- Withdrawing/withholding life-sustaining treatment
- Assent (capacity for)
- Moral distress/burnout/uncertainty
- Tension between the ethical principles of autonomy and beneficence
- Provider autonomy
- Questions regarding safe discharge
- Autonomy and informed consent
- Truth-telling

25

Ethics Committees

- Three-fold mission:
  - Education
  - Policy development
  - Consultation

https://stemcell.ny.gov/ethics-committee

Powell & Blustein. *In: Handbook for Healthcare Ethics Committees.* 2007, p. 1.

26

Ethics Consultation vs. Ethics Committees

Ethics Consultation

Concerned with a particular patient

VS.

Ethics Committee

Concerned with the institution

Powell & Blustein. *In: Handbook for Healthcare Ethics Committees.* 2007, p. 1.

27

Different Models of Ethics Consultation

28

Different Models of Ethics Consultation

- Individual
- Small team
- Committee

https://journalofethics.ama-assn.org/article/what-role-ethics-consultation-moral-habitability-health-care-environments/2017-06

 Berkowitz & Dubler. *In: Handbook for Healthcare Ethics Committees.* 2007, pp. 140-141.

29

Individual Model

- Advantages
  - Fewer logistical barriers
  - Rapid response rate
- Disadvantages
  - Consultant must have all essential knowledge and skills
  - Fewer checks and balances

 Berkowitz & Dubler. *In: Handbook for Healthcare Ethics Committees.* 2007, p. 140.

30

Small Team Model

- Advantages
  - Rapid response rate
  - Diverse perspectives and expertise
  - Less intimidating for patients/family
  - Provides natural forum for support and reflection
- Disadvantages
  - Less efficient than individual model
  - Fewer checks and balances than committee model

https://journalofethics.ama-assn.org/article/what-role-ethics-consultation-moral-habitability-health-care-environments/2017-06

(Berkowitz & Dubler 2007, pp. 141-142)

31

Committee Model

- Advantages
  - Allows for collective proficiency
  - Diverse perspectives and multidisciplinary expertise
- Disadvantages
  - Requires a lot of time
  - Not well suited for urgent needs
  - "Groupthink"
  - Power imbalance (patients/family may feel intimidated by large group)

https://stemcell.ny.gov/ethics-committee

Berkowitz & Dubler. *In: Handbook for Healthcare Ethics Committees.* 2007, pp. 141-142

32

UIHC Ethics Consult Service Structure and Organization

- 24/7 coverage
- Team of consultants led by a director
  - Consultants trained in ethics
  - Administrative support: Program in Bioethics and Humanities
  - Director reports to Chief Medical Officer
  - Oversight provided by Ethics Working Group (monthly review of consults)
- Start date: June 2, 2014
- About 25-30 formal consults per year, and at least as many "curbsides"

UNIVERSITY OF IOWA HEALTH CARE — Institutional Policy Manual

Clinical Care – Policy — **CC.P.74**

SUBJECT/TITLE: **Ethics Consults**

PURPOSE: To define the role, scope, and mechanisms for clinical ethics consults.

SCOPE: Institutional

DEFINITIONS:

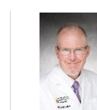
POLICY:

A. Background

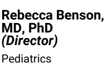
1. The Ethics Consult Service ("Ethics Consult" or "Service") is intended as a clinical resource for UI Health Care personnel. An Ethics Consult is a process by which trained ethics consultants who are members of the Service respond to requests from individuals directly involved in a patient's care. The Ethics Consult is advisory in nature and is designed to:
   a) Identify ethical problems in the care of a particular patient;
   b) Clarify these problems through a careful analysis of the beliefs and values involved;
   c) Promote discussion and dialogue of the beliefs, values, and ethical problems at issue with those directly involved in the patient's care;
   d) Help advise on ethical problems through a process of shared decision-making.

33

Meet the Consultants



Rebecca Benson, MD, PhD *(Director)*	Erica Carlisle, MD	Lauris Kaldjian, MD, PhD	Aaron Kunz, DO, MA, MME	Graeme Pitcher, MBBCh
Pediatrics	Surgery	Internal Medicine	Family Medicine	Surgery



34

34

Case 2: KC

35

KC

- 19-year-old with multiple complications from a motor vehicle accident, transferred from another hospital for ongoing care due to concern that he might need dialysis
- Has a tracheostomy with ventilation most of the day, but did not need dialysis
-
- KC seems to consistently have capacity to make his own decisions, although may have some brain injury from the accident
- He indicated that his goal is to discharge to rehab and then home, but no rehab will accept in current condition
- He is extremely deconditioned and is not adherent to the treatment plan in the ICU, including refusal to get out of bed to bathe or participate with therapy
- The team feels that he is unlikely to achieve stated goal, and wonders if a range of more achievable goals could be presented, including discharge home with support
- The ICU has limited beds, so the team has to turn down other patients for ICU-level care who they feel would benefit more

- What is the ethical issue here?
- What might be the benefits of the different models of ethics consultation for a case like this?

36

KC

- 19-year-old with multiple complications from a motor vehicle accident, transferred from another hospital for ongoing care due to concern that he might need dialysis
- Has a tracheostomy with ventilation most of the day, but did not need dialysis
- Ethical issue?
  - Patient refuses to follow treatment plan that team recommends to achieve stated goals of care
  - Scarce resource allocation
- What else do you want to know?
- Potential reasons
  - Lack of understanding of medical situation?
  - Grief/depression response?
  - Secondary gain?
- Resolution – still admitted and not making progress despite assistance from psychiatry, social work, therapy, etc. ICU has developed criteria to triage the limited resource of beds and presented to Ethics Working Group.

37

References

- Alexander S. (1962 Nov 9). They decide who lives, who dies. *LIFE Magazine*. Accessed from: http://www.nephjc.com/news/godpanel
- Berkowitz KA, Dubler NN. Approaches to ethics consultation. In LF Post, J Blustein, NN Dubler (Eds.), *Handbook for Health Care Ethics Committees* (pp. 140-153). Baltimore: The Johns Hopkins University Press; 2007.
- Chantler C. The role and education of doctors in the delivery of health care. Lancet. 1999;353(9159:1178-1181.
- Core Competencies Task Force. Core competencies for healthcare ethics consultation (2nd ed). Glenview: American Society for Bioethics and Humanities; 2011.
- Fox E, Danis M, Tarzian AJ, Duke CC. Ethics consultation in U.S. hospitals: A national follow-up study. Am J Bioeth. 2022;22(4):5-18.
- Harvard Medical School to Examine the Definition of Brain Death. A definition of irreversible coma. JAMA. 1968;205(6):337-340.
- Jonsen AR. The God Squad and the origins of transplantation ethics and policy. J Law Med Ethics. 2007;35(2):238-240.
- Jonsen AR, Siegler M, Winslade WJ, eds. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, 9e.* McGraw-Hill; 2022.
- Kelly FE, Fong K, Hirsch N, Nolan JP. Intensive care medicine is 60 years old: The history and future of the intensive care unit. Clin Med. 2014;14(4):376-379.
- La Puma J, Toulmin SE. Ethics consultants and ethics committees. Arch Intern Med. 1989;149:1109-1112.
- Nair-Collins M. Expanding the social status of “corpse” to severely comatose: Henry Beecher and the Harvard Brain Death Committee. Perspect Biol Med. 2022;65(1):41-58.
- Patuzzo S, Goracci G, Cilibert R. Thomas Percival. Discussing the foundation of Medical Ethics. Acta Biomed. 2018;89(3):343-348.
- Powell T, Blustein J. Introduction: The nature and functioning of ethics committees. In LF Post, J Blustein, NN Dubler (Eds.), *Handbook for Health Care Ethics Committees* (pp. 1-7). Baltimore: The Johns Hopkins University Press; 2007.
- Purtillo RB. Ethics consultations in the hospital. N Eng J Med. 1984;311(15):983-986.
- Siegler M. Clinical ethics and clinical medicine. Arch Intern Med. 1979;139:914-915.
- Tapper EB. Consults for conflict: the history of ethics consultation. Proc (Bayl Univ Med Cent). 2013;26(4):417-22.
- Teel K. The physician’s dilemma a doctor’s view: What the law should be. Baylor Law Review. 1975;27(1):6-9.
- Wijdicks EFM. How Harvard defined irreversible coma. Neurocrit Care. 2018;29:136-141.

UNIVERSITY OF IOWA HEALTH CARE 38

38

39

Case 3: Ms. F

40

Ms. F

- 30-year-old with schizophrenia and frostbite of left lower extremity
- Committed for psychiatric treatment but despite oral antipsychotic treatment, she still has disorganized thinking and does not have capacity to make medical decisions
- She is refusing recommended treatment of surgical amputation of left lower extremity, feeling that her toes will heal
- She now has complication of sepsis (blood stream infection)
- Since she does not have capacity to make medical decisions and does not have a DPOAHC, her brothers are her next of kin decision-makers
- Her brothers have been hoping that with psychiatric treatment, her capacity will improve, and they have been reluctant to give permission for amputation if she is strongly opposed to it.
- What is the ethical issue here?

41

Ms. F

- 30-year-old with schizophrenia and frostbite of left lower extremity
- Committed for psychiatric treatment but despite oral antipsychotic treatment, she still has disorganized thinking and does not have capacity to make medical decisions
- Ethical issue?
- What else do you want to know?
- Potential reasons
- Resolution

42