Requests and Demands for Inappropriate Medical Treatment

Benjamin J. Infantino, MD
Bruce D. White, DO, JD

ALDEN MARCH BIOETHICS INSTITUTE
AT ALBANY MEDICAL COLLEGE

1

The speakers have no conflicts of interest to disclose.

ALDEN MARCH BIOETHICS INSTITUTE
AT ALBANY MEDICAL COLLEGE

2

Thirty Years Ago the Bedside Ethical Challenges Were Different …

- Recall Karen Ann Quinlan (21 yo F with anoxic brain injury sustained on a ventilator; 1972-1985); Nancy Beth Cruzan (25 yo F with anoxic brain injury sustained with a feeding tube; 1983-1990); Theresa Marie (Terri) Schiavo (25 yo F with anoxic brain injury sustained with a feeding tube; 1990-2005).
- Baby Doe Laws – Bloomington, Indiana (1982) – Stony Brook, New York (1983) – Chambers M. Baby Doe: hard case for parents and courts. New York Times. 1984;Jan 8. – Kopelman LM. Are the 21-year-old Baby Doe rules misunderstood or mistaken? Pediatrics. 2005;115(3):797-802.

3

Demands for Inappropriate Treatment: A Relatively Recent Phenomenon?

- White BD, Hickson GB, Theroit R, Zaner RM. A medical ethics issues survey in five pediatric training programs. American Journal of Diseases of Children. 1991;145: 161-164.
- Breslin JM, MacRae SK, Bell J, Singer PA. Top 10 healthcare ethics challenges facing the public: views of Toronto bioethicists. BMC Medical Ethics. 2005;6:5.

4

In the Early 1990s Something Changed!

- Helga Wanglie - Minnesota District Court, Hennepin County, Probate Court Division, PX-91-283, July 1, 1991 - Angell M. The case of Helga Wanglie. N Engl J Med. 1991;511-512. - Miles S. Informed demand for "non-beneficial" medial treatment. N Engl J Med. 1991;325:512-515.
- Catherine F. Gilgunn - Kolata G. Withholding care from patients: Boston case asks, who decides. New York Times. 1995;Apr 3:B8. - Mass. Jury: doctors were right to withdraw life support. Amer Med News. 1995;May 8:10.

5

In the Early 1990s Something Changed!

- Sonya Causey - Causey v. St. Francis Medical Center, 719 So.2d 1072 (La. Ct. App. 1998)
- Texas Health and Safety Code . Advance Directives. 1999. Chapter 166. 166.046. - Pope TM. Medical futility statutes: no safe harbor to unilaterally refuse life-sustaining treatment. Tennessee Law Review. 2007;75:1–81. - Fine RL. Point: The Texas advance directives act effectively and ethically resolves disputes about medical futility. Chest. 2009;136:963–967.
- Barbara Howe - Kowalczyk L. Woman dies at MGH after battle over care: daughter fought for life support. Boston Globe. June 8, 2005.

6

In the Early 1990s Something Changed!

- Baby L (23-month-old NICU graduate) - Paris JJ, Crone RK, Reardon F. Physicians' refusal of requested treatment: the case of Baby L. N Engl J Med. 1990;322(14):1012-1015.
- 5 year old male with a closed head injury placed on ECMO - Paris JJ, Schreiber MD, Statter M, Arensman R, Siegler M. Beyond autonomy – physicians' refusal to use life-prolonging extracorporeal membrane oxygenation. N Engl J Med. 1993;329(5):354-357.
- Baby K (anencephalic) - In re Baby K, 16 F.3d 590 (4th Cir. 1994) - Hospital appeals decision ordering treatment for baby missing a brain. New York Times. 1994;Jun 11:12A. - Baby K – now Stephanie – turns 2. USA Today. 1994;Oct 13:3A.

7

Recall Medicine's Ancient Traditions

- Hippocrates:
  - Three major goals of medicine: cure, relieve suffering, and "refus[e] to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless."
- Plato:
  - "to attempt futile treatment is to display an ignorance that is allied to madness."

Miles SH. *The Hippocratic Oath and the Ethics of Medicine*. New York: Oxford University Press, 2004.

Siegler M. The physician-patient accommodation: a central event in clinical medicine. Arch Intern Med. 1982;142:1899-1902.

8

This is more than just "poor communication."

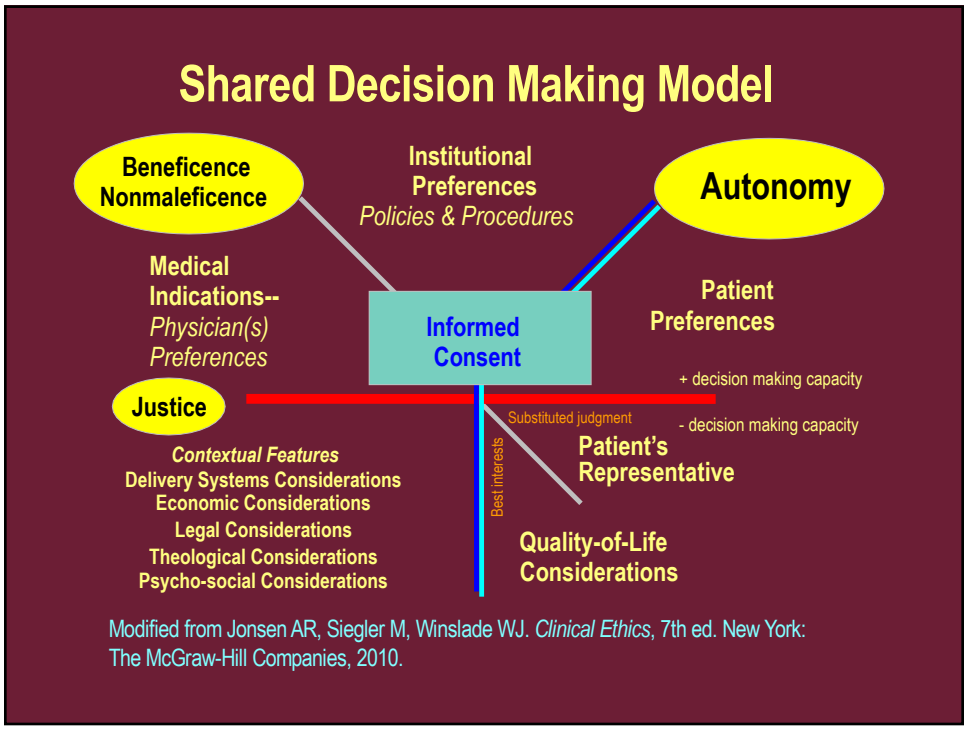
See Rider EA, Keefer CH. Communications skills competencies: definitions and a teaching toolbox. Med Educ. 2006; 40:624-629; and Humphrey N. Warning signs: program assesses malpractice risk and advises physicians on possible danger ahead. Vanderbilt Medicine. 2012;Feb. Available at: http://www.mc.vanderbilt.edu/vanderbiltmedicine/index.html?article=12034 (accessed September 2, 2012).

9

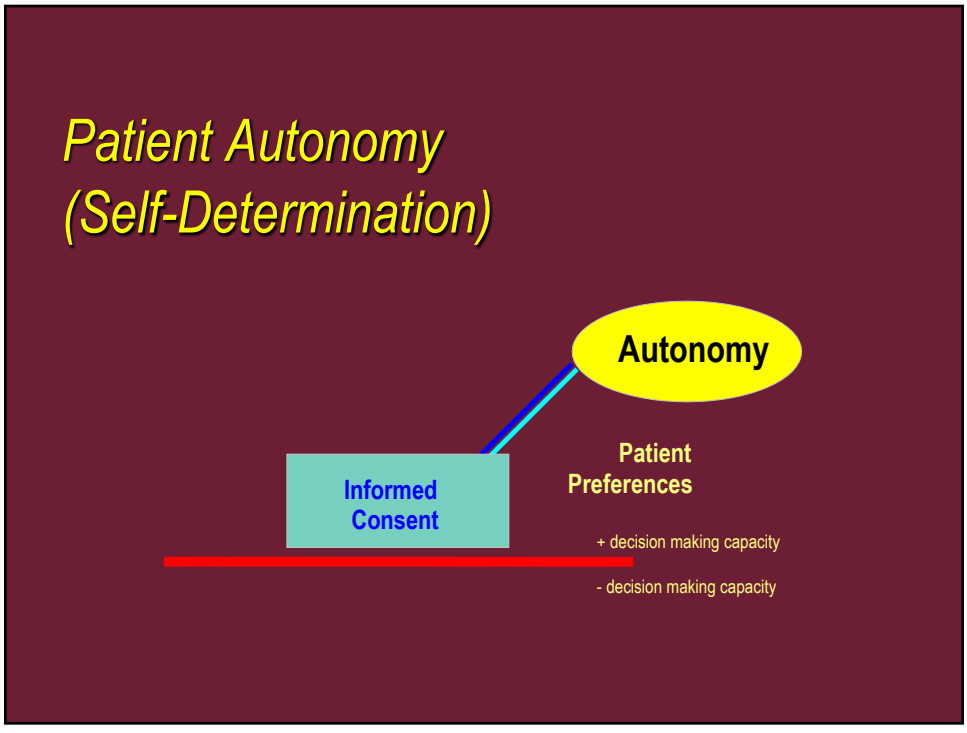
Objectives

- Describe the various obligations that arise from the physician-patient relationship.
- Explain how physicians and patients and surrogates face competing personal and professional expectations in the physician-patient relationship particularly when confronting demands for inappropriate treatment.
- Using case examples, discuss possible role conflicts in demands for inappropriate treatment.
- Highlight a few strategies for resolving and avoiding potential role conflicts in the physician-patient relationship and demands for inappropriate treatment.

10

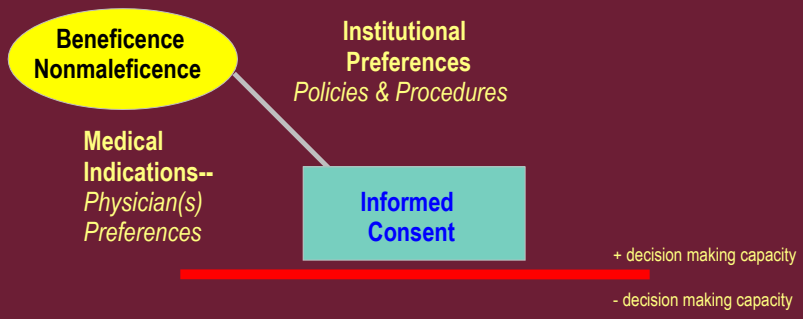

Shared Decision Making Model
Beneficence
Nonmaleficence
Institutional
Preferences
Policies & Procedures
Autonomy
Medical
Indications--
Physician(s)
Preferences
Informed
Consent
Patient
Preferences
+ decision making capacity
- decision making capacity
Justice
Substituted judgment
Best interests
Patient's
Representative
Contextual Features
Delivery Systems Considerations
Economic Considerations
Legal Considerations
Theological Considerations
Psycho-social Considerations
Quality-of-Life
Considerations
Modified from Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics, 7th ed. New York:
The McGraw-Hill Companies, 2010.

11


Patient Autonomy
(Self-Determination)
Autonomy
Informed
Consent
Patient
Preferences
+ decision making capacity
- decision making capacity

12

Physician Beneficence-Nonmaleficence (Benefits-Burdens) Assessment



13

So, what does one mean by "role conflict"?

- Think in terms of the Jonsen-Siegler-Winslade clinical ethics model's "four boxes."
- The physician's role is to take the information and translate it into "medical indications."
- The patient's role is to take the medical indications information and state "preferences."
- A shared decision leads to informed consent.

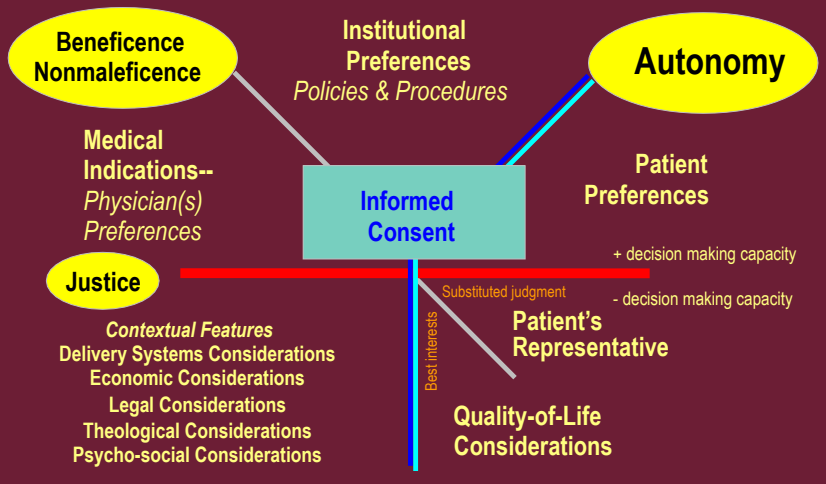
14

Role conflict typically occurs when someone gets into another's "box."

- The physician unilaterally makes decisions without understanding the patient's preferences (paternalism). This provided one of the early reasons for a training emphasis on medical ethics (also recall technological advances [1960s] and research abuses [1965-1972] with the National Commission's work culminating in the 1978 Belmont Report.)
- The patient or patient's surrogate attempts to practice medicine. There were early signs of this conflict in the DNR debate; it is is currently playing out in the medical futility debate that probably will be resolved legislatively (eg, Texas).

15

Shared Decision Making Model



Modified from Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics*, 7th ed. New York: The McGraw-Hill Companies, 2010.

16

Objectives

- Describe the various obligations that arise from the physician-patient relationship.
- Explain how physicians and patients and surrogates face competing personal and professional expectations in the physician-patient relationship particularly when confronting demands for inappropriate treatment.
- Using case examples, discuss possible role conflicts in demands for inappropriate treatment.
- Highlight a few strategies for resolving and avoiding potential role conflicts in the physician-patient relationship and demands for inappropriate treatment.

17

Case One

A six-year-old male is readmitted to the hospital for second time in two weeks for overnight observation (which stretches into several days); the mother believes the child has mitochondrial disease even though the patient has been seen by a Boston specialist and the specialist does not agree at this point; the mother reports that the child has unusual neurological symptoms that have not been seen by several providers after extensive evaluation; the mother reports that the child is not eating well and has lost weight, but this too is inconsistent with prior documentation and observation

18

Case Two

The father of a 11-year-old male with persistent symptoms of Lyme disease (post-treatment Lyme disease syndrome) is disappointed when the team refuses to order intravenous antibiotics as prescribed by the patient's Lyme disease specialist when the patient is admitted to the hospital for a fever of unknown origin.

19

Case Three

The patient's mother insists on hospitalization because the child's behavior is "out of control." After the child is settled in a hospital bed, the mother goes to the cafeteria for coffee; when she returns from the cafeteria, she sees nurses ready to draw blood for routine studies ordered by the child's neurologist. She goes berserk because she doesn't want any blood drawn.

20

Case Four

A nine-year-old injured three years ago in an automobile accident has not recovered well. She was never able to participate in a rehabilitation program. She has numerous medical problems and is institutionalized. She is maintained with g-tube feedings, but has slow gut syndrome. She has central-SIADH and requires fluid status monitoring. She was admitted to the hospital six months ago for palliative orthopedic surgery. The surgery wound still has not heal. The mother insists on daily routine blood chemistries even though the values have remained stable for weeks.

21

Case Five

A 15-year-old female with presumed mitochondrial disease refuses to eat; the mother insists on continuous total parental nutrition (TPN) feedings.

22

Case Five: The Patient

- 15-year old female with history of mitochondrial disorder and gastrointestinal/nutritional sequelae:
  - Inadequate oral intake with tube feeding dependence.
  - Gastroparesis.
    - Complaints of abdominal pain/enteral feeding intolerance.
  - Nausea with prior vomiting.
  - Poor weight gain related to the above.

23

Case Five: History

- Seen in 2007 by Pediatric Neurology for absence seizures, global developmental delay, and headaches.
- Seen by Pediatric Gastroenterology at that time for feeding refusal and question of eosinophilic esophagitis.
- Liquid-phase gastric emptying study on 10/21/08 normal.

24

Case Five: History

- Initial consult with Genetics on 1/21/09.
- At that time urine organic acids, plasma amino acids, acylcarnitine profile, and ammonia normal.
- However, lactate/pyruvate ratio elevated at 72 (normal <20) and alanine/lysine ratio marginally elevated at 3.61 (normal <3).
- Recommendation to obtain a SNP microarray analysis, carbohydrate deficient transferrin, SLO screen, repeat plasma amino acids/lactate/pyruvate.
  - No new abnormalities but prior abnormalities consistent.

25

Case Five: History

- On 2/11/09, patient underwent concurrent placement of gastrostomy tube and muscle biopsy.
  - Suggested deficiency of complex IV.
- Gastrostomy converted to GJ tube in 4/09 due to complaints of pain with gastric feedings.
  - Port-a-Cath placed as well.
- Records indicate that by 6/09, patient on TPN.

26

Case Five: History

- Evaluated at Boston Children's in 10/09.
  - GI motility testing reported normal.
  - Admitted for CVL infection with Staph aureus x1 and non-aureus Staph x2.
  - Admitted to AMC PICU 12/31/09 with another sepsis episode with E. coli and AKI.
  - Patient remained on TPN following discharge.

27

Case Five: History

- Line infections 9/10, 10/10, and 10/11.
- Admitted to AMC 10/11 for another central venous line infection.
- Multiple ED visits for line malfunction and other related complications.

28

Case Five: History

- Re-evaluation of motility in 11/11 reported to be indicative of “severe gastroparesis”.
  - Specialist through Tufts’ Floating Hospital for Children.
- Off of TPN by 12/12.
- At subsequent visits, it is frequently documented that patient’s mother felt she did best and gained weight best when on TPN and formula feeds.

29

Case Five: History

- Reports starting in 8/13 that patient not tolerating feeds due to pain and nausea, prompting multiple modifications to tube feeding regimen.
  - Weight loss documented.
- September 2014 to March 2015 patient off both TPN and tube feeds - all nutrition taken by mouth.
- Following that time, patient resumed complaints of pain and nausea.

30

Case Five: September 25, 2015

- Seen in clinic by primary Pediatric Gastroenterologist.
- Complaints from patient and mother about PICC line and desire expressed for more permanent line to be placed.
- Decision made to admit to hospital the following week for re-evaluation of nutritional status as patient not receiving sufficient amounts and weight suffering.
  - Enteral versus parenteral approach?
  - "Fresh set of eyes" with new staff member.

31

Case Five: My Initial Thoughts

- Complicated patient with extensive history in need of adequate nutrition.
- Concern with CVL infections and history of other associated complications.
- Interest in proceeding with enteral nutrition unless solid objective evidence of non-tolerance.

32

Case Five: 9/28/2015-10/2/2015

- Home nutrition on admission:
  - Ensure Clear, 3-4 servings by mouth each day
  - Peptamen AF with MCT oil at max of 25 mL per hour through GJ.
    - Feedings often paused due to patient complaints of nausea.
  - PO as tolerated.
    - Patient recently seen to be drinking large iced coffee and other similar drinks.

33

Case Five: Strategies for Enteral Feeding

- Adjustment of antiemetic medications.
- Use of alternative formulas (Pediasure Peptide, Neocate).
- Addition of modulars (microlipids).
- Temporary substitution of parts of feeding with water.

34

Case Five: The Patient

- Complained repeatedly of pain with tube feedings and requests were made to decrease rate from 25 mL/hr to 15 mL/hr.
- Tube confirmed in good position with contrast X-ray.
- Objectively, patient had no vomiting, diarrhea, or abdominal distention.
- Noted to often be tachycardic in the evening, which Mom attributed to "autonomic storm" from mitochondrial disorder.

35

Case Five: The Mother

- Became increasingly displeased as the week went by with attempts at enteral feeding.
- Along with patient, demanded central line placement and TPN.
  - Invoked calling their lawyer.
  - Invoked having patient emancipated so she could make providers put her on TPN.
  - "Quality over quantity."
- Accusations of physician not listening or caring.

36

Case Five: The Physician

- Spent several hours throughout the week discussing care with family in conjunction with nursing, social work, and dietitian.
- Stressed concern that patient was not showing objective signs of feeding intolerance that would merit TPN.
- Expressed my own frustration that various attempted interventions were either refused or cut short quickly.

37

Case Five: Meanwhile…

- Patient not gaining, and has even lost a little weight.
  - Thought to be related to patient taking less than 1 Ensure Clear per day and virtually no PO otherwise, which she had been doing outpatient.
  - Failed attempts at increasing enteral nutrition calories, which were insufficient on admission.
- Patient's mother demanded Ethics consult, which was agreeably ordered.
  - Risk Management contacted as well.

38

Case Five: Ethics Consultation

- Discussion to follow…
- Ultimate recommendations were:
  - One-to-one sitter to ensure family adhering to recommendations and also to allow witness on behalf of family that they were adhering.
  - Further Social Work involvement.
  - Second opinion, from either another pediatric gastroenterologist or an adult gastroenterologist.

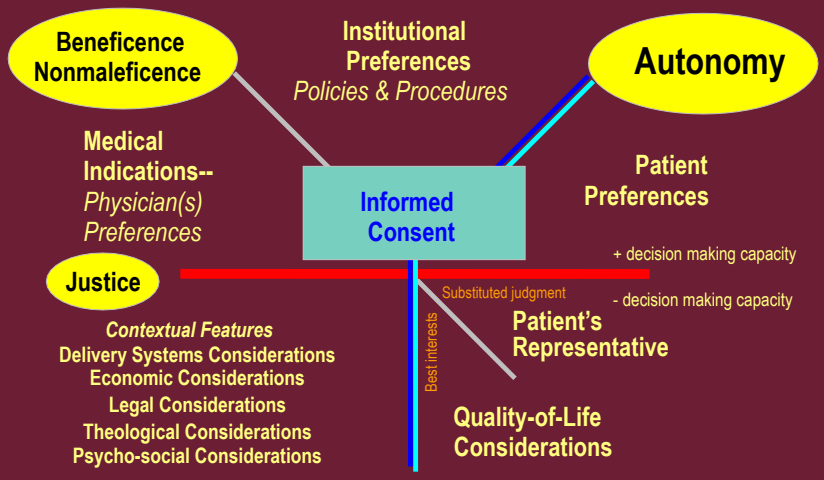
39

Case Five: In the End…

- Patient and mother quite upset with recommendations.
- Worried that CPS was going to be involved.
- Agreement reached that patient would be discharged but with assurance of follow-up with primary Pediatric Gastroenterologist the next week.

40

Shared Decision Making Model



Modified from Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics*, 7th ed. New York: The McGraw-Hill Companies, 2010.

41

Role conflict situations are challenging.

- Doctors and nurses and the team want to help patients. It is difficult in the beginning to establish clear boundaries because the team wants to accommodate parents and patients as much as possible and because of medical uncertainties. Once parents "with permission" begin to edge into the doctor's box it will be more awkward to set clearer boundaries. These cases consume time and emotional energy. Perhaps the extreme is a factious illness by proxy case?
- Doctors avoid confrontation and fear legal entanglements.
- Doctors and hospitals avoid adverse publicity.

42

Doctors and Teams Should Consider Resolution Strategies Early

- From the very beginning, it would be helpful if patients and their legally authorized representatives understood their right as responsibilities. See Lucille Packard Children's Hospital Patient Rights and Responsibilities brochure.
- Doctors and nurses and teams should role-play scenarios in anticipation of these kinds of problems.
- Be alert to responses such as "the doctor doesn't care"; "the doctor isn't listening to me"; "the doctor is arrogant and condescending"; "I'll sue you." (At this point, frustrated parents are becoming more desperate.)

43

As an Aside: Legal Threats or Medical Malpractice Concerns?

- Giving into the threat "I'll sue you" only makes the situation worse. It just shows that the team may not be making recommendations in the patient's best interests but perhaps in their own best interests. It may prove unprofessional conduct.
- Pediatricians as a specialty are less likely to be sued (3.1% v. 7.4%). Jena AB, Chandra A, Seabury SA. Malpractice risk among US pediatricians. Pediatrics. 2013;131(6):1148-1154. Liability resulted most often from failure to diagnose meningitis and cancer.
- The best defense in against a malpractice claim is that the doctor met the standard of care.

44

As an Additional Aside: Child Protective Services (CPS) Involvement?

- CPS may be interested if one suspects "abuse" or "neglect." "Neglect" includes medical neglect.
- CPS may not be interested if the child is hospitalized because the child is in a "safe" environment. CPS may become more interested with repeated calls from numerous providers.
- For doctors leery of legal entanglements, sometimes CPS involvement can be just at protracted, cumbersome, and as chilling as a threatened malpractice case. See https://www.bostonglobe.com/metro/2014/12/07/difficult-return-hospital-for-justina-pelletier/u4JXzmt5YsmWhYk95za2aK/story.html.

45

Doctors and Teams Should Consider Resolution Strategies Early

- As early as possible into the hospitalization, the teams should establish clear boundaries as indicated.
- Identify the more trusted doctor as the point person contact.
- All involved physicians should be agreed on a plan of care.
- Take care to document important exchanges; use quotes.
- Be cautious about having conversations without allies present. Enlist support from nurse managers, clinical nurse specialists, social services, patient affairs, pastoral care, ethics, risk management, legal counsel, and administration.
- Use the hospital's procedural conflict resolution guideline.

46

Doctors and Teams Should Consider Resolution Strategies Early

SUBJECT: RESPONDING TO REQUESTS OR DEMANDS FOR INAPPROPRIATE MEDICAL TREATMENT

Albany Medical Center is committed to open and honest communication with patients. On occasion, a patient or the patient's legally authorized representative will request or demand a treatment that the Attending Physician and the medical team believe is medically inappropriate. Medically inappropriate treatment means "a treatment that does not confer greater proportional benefits than burdens to the patient according to reasonable medical standards." Treatment may be medically inappropriate if it cannot be expected to restore function to the patient or to achieve the expressed goals of the informed patient. It is the responsibility of the patient's Attending Physician to determine whether or not a treatment option is medically inappropriate or medically unnecessary according to generally accepted current reasonable medical standards. Moreover, in such situations, the Attending Physician should clearly be acting in the patient's best interests to maximize good and minimize harm.

47

Doctors and Teams Should Consider Resolution Strategies Early

- The Albany Medical Center Guideline on Requests or Demands for Inappropriate Care as been approved by the Board of Directors and aligns team and administrative goals in patient care.
- The Guideline is supported by national authorities. See UpToDate: "Responding to Requests for Potentially Inappropriate Therapies in Adults," June 4, 2015.

48

Recall the Texas Advance Directives Statute (1999) As a Legal Response

The Sun Hudson case was the first time the statutory schema was invoked. The patient was an infant hospitalized at Texas Children's Hospital in Houston with a thanatophoric dwarfism was removed from a ventilator over the mother's objection.

http://www.chron.com/news/houston-texas/article/Baby-born-with-fatal-defect-dies-after-removal-1498268.php

49

Role conflict possibilities will become more challenging.

- Physicians and patients will be forced into awkward quasi-physician-patient relationships (eg, managed care, employed physicians, exclusive inpatient providers).
- Organizations will attempt to get into both the doctor's and patient's box.
- Our communities are becoming more diverse and with diversity sometimes there is more distrust.
- Patients will have more chronic problems.
- The justice quadrant may become "society's box" with resources becoming more scarce.

50

These cases explain and test the true nature of professionalism.

As Pellegrino emphasized: "[A doctor] binds him[- or herself] to competence as a moral obligation" and "places the well-being of those he [or she] presumes to help above own personal gain."

– Langer, Emily. "Edmund D. Pellegrino, prominent bioethicist, dies at 92." *The Washington Post.* June 19, 2013. http://www.washingtonpost.com/local/obituaries/edmund-d-pellegrino-preiminent-bioethicist-dies-aat-92/2013/06/19/34a3e97a-d82f-11e2-9d14-895344c13c30_s (accessed January 5, 2015).

51

Objectives

- Describe the various obligations that arise from the physician-patient relationship.
- Explain how physicians and patients and surrogates face competing personal and professional expectations in the physician-patient relationship particularly when confronting demands for inappropriate treatment.
- Using case examples, discuss possible role conflicts in demands for inappropriate treatment.
- Highlight a few strategies for resolving and avoiding potential role conflicts in the physician-patient relationship and demands for inappropriate treatment.

52


Questions? Comments?
ALDEN MARCH BIOETHICS INSTITUTE
AT ALBANY MEDICAL COLLEGE

53