Futility, State Law, and the Fate of Children

Mary Anderlik Majumder, JD, PhD

Center for Medical Ethics and Health Policy

Baylor College of Medicine

Children's
Treuman Katz
Center for Pediatric Bioethics
Seattle, Washington

Overview

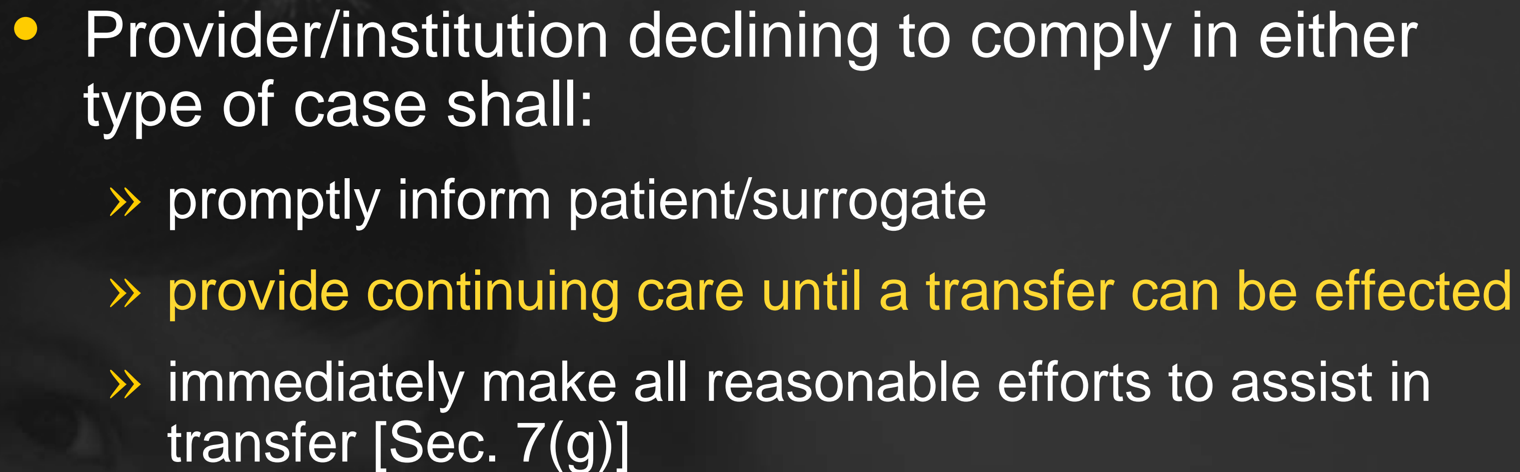
- 3 models for state law addressing “futility” (UHCDA, affirmation of health care provider rights, TADA).
- The Emilio Gonzales case, objections to the TADA-Texas model, and possible policy responses.

- National Conference of Commissioners on Uniform State Laws approved in 1993.

- Law in 8 states (AL, AK, DE, HI, ME, MS, NM, WY).

UHCDA: Text

- A health-care provider or institution may decline to comply with an individual's instruction or health-care decision:
  - » for reasons of conscience [Sec. 7(e)]
  - » that requires medically ineffective health care or health care contrary to generally accepted health-care standards [Sec. 7(f)]
    - Comment: Medically ineffective health care means treatment which would not offer the patient any significant benefit.



- Provider/institution declining to comply in either type of case shall:
  - » promptly inform patient/surrogate
  - » provide continuing care until a transfer can be effected
  - » immediately make all reasonable efforts to assist in transfer [Sec. 7(g)]

UHCDA: Analysis

- Goal: Give legal weight to the moral claims of patients and their surrogate decision-makers and the moral claims of health care professionals and institutions.

- Problem: In treating a conflict over withdrawal (or withholding) of treatment judged <u>appropriate</u> by the physician and a conflict over withdrawal of treatment judged <u>inappropriate</u> by a physician as equivalents, both resolvable by rule of “treat-until-transfer,” *in practice* favors the claims of patients and surrogates.

- Why?
  - Post-*Quinlan* and *Cruzan*, usually not difficult to find a physician/institution willing to comply with a family request to withdraw treatment, if such a decision is permissible under state law.
  - However, consensus that the treatment sought is inappropriate will frequently cause other physicians/ institutions to refuse to accept a transfer - as indeed it should.

Alternatives I

- Affirm that health care professionals/institutions are not required to provide inappropriate treatment.
  - » Little guidance on what is owed to patients/surrogates.

    - Ex: Nothing in AD legislation “shall be construed to compel or authorize a health care provider or health care facility to administer medical treatment that is otherwise illegal, **medically inappropriate**, or contrary to any federal or state law” [Colo. Rev. Stat. § 15-14-506]
  - » In this sense, claims of professionals and institutions are privileged.

Alternatives II: TADA

- Like UHCDA, an attempt to balance competing moral claims.
- Unlike UHCDA, contains provisions tailored to conflicts in which a physician refuses a request for treatment citing inappropriateness.
- Unlike laws affirming that inappropriate treatment need not be provided, specifies a procedure that incorporates a number of due process rights for patients/surrogates.

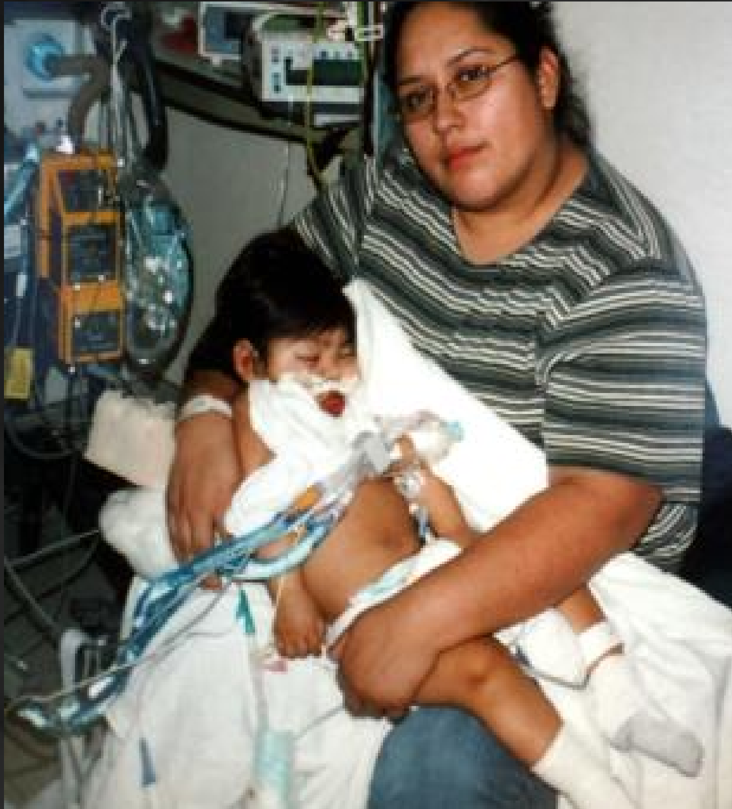
TADA: Text

- Medical or ethics committee reviews attending physician's refusal.
- 48-hour notice to patient/surrogate (including explanation of process and information from statewide referral registry) and right to attend meeting.
- Written explanation of decision to patient/surrogate and to record.
- Reasonable effort to transfer patient if attending, patient, or surrogate does not agree with decision.
- If the committee supports attending, treatment can be discontinued on the 10th day after the explanation is given to patient/surrogate.
  - » Life-sustaining treatment cannot be described in patient record as unnecessary until 10-day period has expired.
  - » Court can extend period if it finds, by a preponderance of the evidence, a reasonable expectation that a physician or health care facility that will honor the patient's directive will be found if the extension is granted. [Tex. Health & Safety Code, § 166.046]

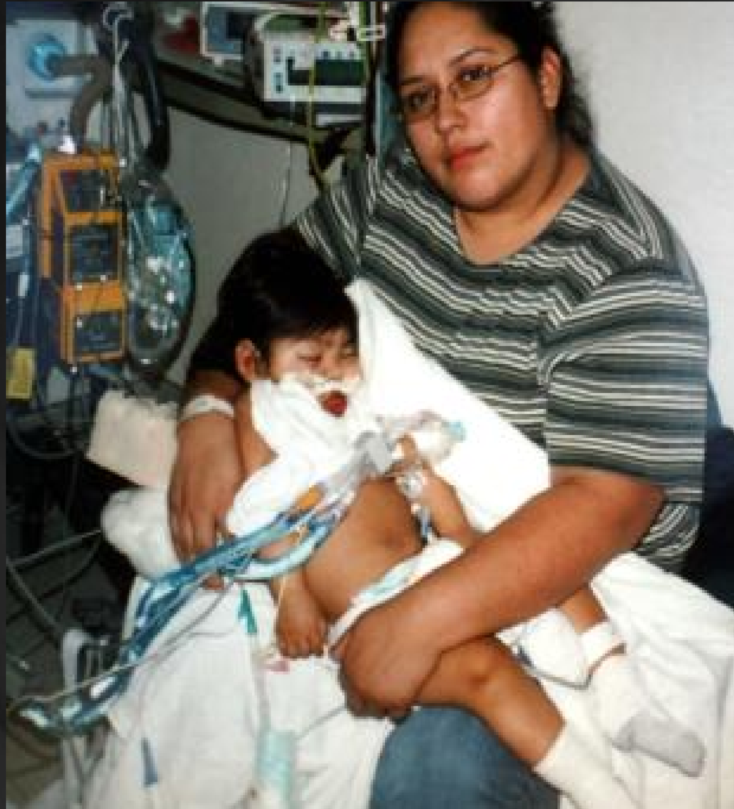
Four Objections

- The due process rights incorporated in the law are inadequate, especially in light of the power imbalance.
- Other physicians and institutions may refuse to accept a transfer for reasons other than their concurrence in the determination of inappropriateness.
- These conflicts are really about values and in that domain health care professionals and institutions enjoy no special expertise.
- Some of the harms to patients identified by health care professionals in connection with continuing life-sustaining treatment are problematic.

One Case



Kelly West
Austin American-Statesman



Due Process Inadequacies

- Although most individuals within most health care institutions desire a flexible, compassionate process:
  - » TADA itself is indifferent to prior efforts to mediate, current efforts to respond to patient/family needs beyond serving notices and assistance with transfer (in Emilio's case, such efforts were substantial).
- Policy responses:
  - » Bring in the lawyers?
  - » Require prior ethics consultation (unless declined), name a liaison, and provide information on patient's condition with time for review in advance of meeting.

Non-Medical Barriers to Transfer

- Other physicians and institutions may refuse to accept a transfer, even if they consider the treatment request appropriate, because:
  - » Accepting a transfer would not make economic sense.
  - » A family that would challenge a physician's judgment and make a fuss is bound to be "difficult."
    - Although available data suggests that transfers do occur in at least some of these conflict cases.
- Policy responses:
  - » Guarantee full payment from state funds?
  - » Accept the first risk as but one of many flowing from our failure to achieve universal access to health care, while collecting data to monitor.

Value vs. Medical Judgments

- Judgments of inappropriateness unavoidably include a value component.
  - » Health care professionals have no special expertise related to values generally.
    - Professional training and experience do, however, give special insight into the way medical conditions and procedures affect the body, insight that has ethical implications (especially compelling where surrogate, not guided by advance directive, is pressing for treatment).
- Policy solutions:
  - » Specify that the inappropriateness is medical?
  - » Require an expert second opinion as a reasonable internal test for concordance between the attending physician's judgment and professional standards, in addition to review by committee.

Problematic Claims re Harms to Patients

- Individuals unconscious due to sedation or underlying medical condition described as “suffering” without elaboration, or suggestion that dependence on tubes or a ventilator is inherently “undignified.”
  - » In Emilio’s case, specific findings supported view that he (not just those compelled to continue aggressive LST) experienced suffering, and that the damage done to his body in the absence of any corresponding benefit constituted an assault on his dignity.
- Policy responses:
  - » Education, education, education.

Questions?