Trying To Do The Right Thing

Ethical Framework for Medical Decision-Making in the Pediatric ICU

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Outline

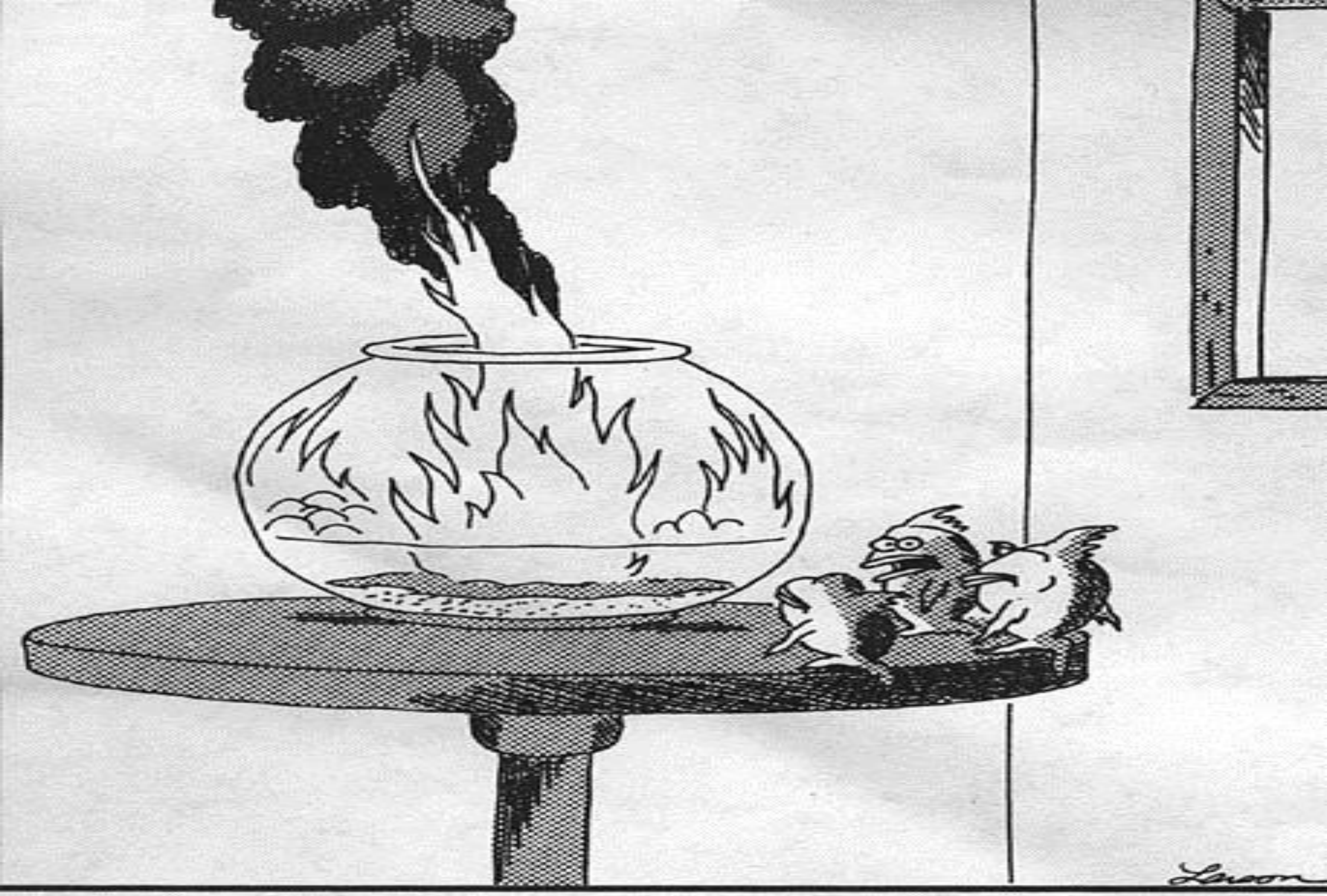
<u>Ethical framework for medical decision making in children</u>

- Best interest standard
- Permission and assent
- Special circumstances

  - adolescents   - abuse/neglect

  - religious objections - disagreements about care

  - end of life



"Well, thank God we all made it out in time. …
'Course, now we're equally screwed."

Medical Decision Making: Adults

- Gold standard - patient’s wishes
- Silver standard - advance directives
- Bronze standard - substituted judgment
- Standard of last resort - best interest

Medical Decision Making: Children

- Best interest standard *(Parham v JR)*
- Who gets to decide what is in the best interest of a child?

  - Parents are in the best position to place the treatment of their child's medical condition into the context of their own value system and hopes for their child's future
- "Basic Interests"   Richard Miller

Medical Decision-making: Children

- Parents are the presumed decision makers for their children
- Not because they “own” their children
- But because we presume parents will make decisions in their child’s best interest

Parents and Decision-making

- In most cases, a range of decisions is compatible with the patient's best interest

Acceptable Range

"Too little" treatment ⟷ "Too much" treatment

Parents and Decision-making

Reasons why parents may choose outside this range:

- Religious beliefs
- Failure to comprehend or rationally consider alternatives
- Personal or cultural values
- External constraints (e.g. financial)

Parents and Decision-making

When parents choose outside this range:

- Cannot simply override parents, except in an emergency situation to save the child's life
- Must challenge the parent's decision in court

Case of P

11 months old little boy with severe chronic lung disease who is ventilator dependent

Suffers a cardiac arrest at home and is resuscitated but has severe brain damage resulting in a persistent vegetative state

Case of P

- Medical team recommends withdrawal of life-sustaining medical treatment
- Parents disagree and wish to continue all therapy and keep their child alive
- Medical team believes that keeping this child alive is “wrong” and asks for an ethics consultation

Clinical Ethics

An interdisciplinary activity to identify, analyze, and resolve ethical problems that arise in the care of particular patients. The major thrust of clinical ethics is to work for outcomes that best serve the interests and welfare of patients and their families.

Fletcher J. Maryland Law Review 1991;50:859

Limitation Of Parental Rights

- Abuse and/or neglect
- Incompetent parents
- Conflict of interest
- Conflict between the parents regarding the medical decision
- Where a minor has expressed an opinion

Causes of Disputes

Surrogate

- Distrust
- Cognitive issues
- Psych & Emotional Issues
- Values, religion, & miracles

Provider

- Patient suffering
- Respect autonomy
- Integrity
- Moral distress
- Stewardship

Futility

- Physiological futility
  - Interventions that are considered inappropriate because they have a zero percent chance of being effective
  - No normative disagreement
  - Based solely on clinical knowledge
  - Limited applicability
  - Rarely certain that there is 100% no effect

Futility

- Quantitative futility
  - Clinical studies and scoring systems can provide an empirical basis for establishing percentage thresholds
  - Ethically disputable
  - Unclear where the threshold should be set
  - Unable to determine whether a given threshold standard applies to a particular patient

Futility

- Qualitative futility
  - Treatment is medically inappropriate when the prospective benefits are outweighed by its burdens (causes suffering)
  - Treatment is inappropriate when it cannot provide the minimum quality-of-life worth living
  - Who decides quality-of-life?
  - Value judgment

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

Gabriel T. Bosslet, Thaddeus M. Pope, Gordon D. Rubenfeld, Bernard Lo, Robert D. Truog, Cynda H. Rushton, J. Randall Curtis, Dee W. Ford, Molly Osborne, Cheryl Misak, David H. Au, Elie Azoulay, Baruch Brody, Brenda G. Fahy, Jesse B. Hall, Jozef Kesecioglu, Alexander A. Kon, Kathleen O. Lindell, and Douglas B. White; on behalf of The American Thoracic Society *ad hoc* Committee on Futile and Potentially Inappropriate Treatment

This Official Policy Statement of the American Thoracic Society (ATS) was approved by the ATS, January 2015, the American Association for Critical Care Nurses (AACN), December 2014, the American College of Chest Physicians (ACCP), October 2014, the European Society for Intensive Care Medicine (ESICM), September 2014, and the Society of Critical Care Medicine (SCCM), December 2014

Summary of Recommendations

- Recommendation 1
  - Institutions should implement strategies to prevent intractable treatment conflicts, including proactive communication and early involvement of expert consultation

Summary of Recommendations

- Justification
  - Collaborative decision making is a fundamental aspect of good medical care and therefore a valuable and ethical goal to foster
  - Once conflicts become intractable, there are only “second best” resolution strategies, which are likely to be protracted and burdensome to all parties involved
  - Most disagreements arise not from intractable value conflicts but from breakdowns in communication and are amenable to communication interventions

Summary of Recommendations

- Recommendation 2
  - The term <u>“potentially inappropriate” </u>should be used, rather than “futile”, to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them

Summary of Recommendations

- Justification
  - The word “inappropriate” conveys more clearly that the assertion being made by clinicians depends on both technical medical expertise and a value-laden claim, rather than strictly a technical judgment
  - The word “potentially” signals that the judgments are preliminary, rather than final

Summary of Recommendations

- Conflict-resolution Process
    1. Enlist expert consultation to aid in achieving a negotiated agreement
    2. Give notice of the process to surrogates
    3. Obtain a second medical opinion
    4. Provide review by an interdisciplinary hospital committee
    5. Offer surrogates the opportunity for transfer to an alternate institution
    6. Inform surrogates of their opportunity to pursue extramural appeal
    7. Implement the decision of the resolution process

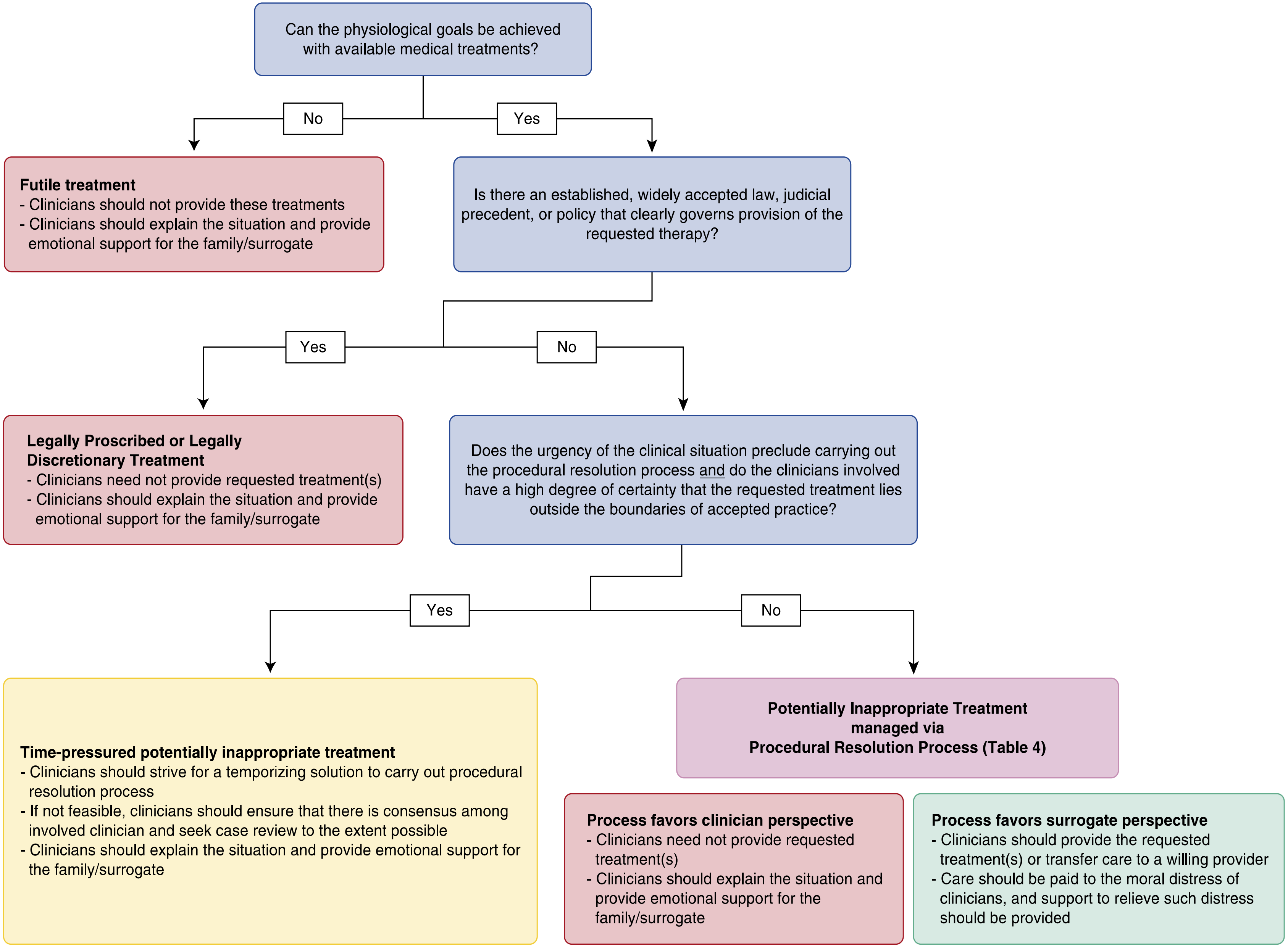


Figure 1. Recommended approach for management of disputed treatment requests in intensive care units.

Parents win fight over care for their ill son

Judge rules couple can try diet instead of chemotherapy

MICHAEL SANGIACOMO
Plain Dealer Reporter

CANTON — Teresa and Greg Maxin did not plan to challenge the medical establishment.

They just wanted their 7-year-old son to stop hurting.

A Stark County judge's ruling yesterday that the Maxins cannot be forced to treat Noah's leukemia with chemotherapy allows the parents to try to control the disease by watching his diet. The ruling is believed to be the first in Ohio in a case in which a county had concluded that parents were pursuing an ineffective treatment.

Noah

"These are not parents who refused medical treatment or who elected to take Noah to a witch doctor or a shaman," Judge David Stucki ruled.

He said they carefully researched and selected an alternative treatment, which was their right.

"Gregory and Theresa Maxin are loving parents involved in a battle to save Noah from the disease of leukemia," Stucki said.

"The last thing they all need is to simultaneously do battle with the medical and legal community over their own well informed, researched and compassionate decisions regarding medical care for Noah."

Stark County's Department of Job and Family Services had accused the couple of neglect because they refused to continue their son's chemotherapy.

"That really hurt them," said Gregory Beck, attorney for the family. "There is no way to sugarcoat that word — 'neglect' — especially when all they wanted to do was to make life easier for their son."

SEE TREATMENT | A6

A rainbow for Noah

Judge's decision to let 7-year-old's family treat his cancer by alternative medical means puts the right people in charge

No one can doubt that Teresa and Greg Maxin are trying to do what's best for their son, Noah, whose leukemia was diagnosed in May.

They have spent months researching treatment options, have availed themselves of traditional medical approaches and now have the boy on a dietary regimen prescribed by a doctor whose methods are nontraditional.

Noah is 7. If he can somehow beat the dis-

analysis.

He saw through the county's argument that if the traditional treatment isn't followed, Noah's cancer might return. That's true, as far as it goes, but it is also true that the cancer stands a good chance of coming back even if chemotherapy is administered.

But aside from the technical, medical arguments, Stucki recognized that in a situation in which every person and agency concerned is

When Parents Disagree With Recommended Treatment

- The greater the risk to the child in honoring the parent’s wishes, the greater the justification for limiting parental rights
- Benefits and burdens of the proposed treatment need to be weighed
- The chance of a successful outcome is factored into the decision
- “Harm Principle” Diekema

Harm Principle

1. By refusing consent are the parents placing their child at significant risk for serious harm?
2. Is the harm imminent, requiring immediate action to prevent it
3. Is the intervention that has been refused necessary to prevent serious harm?

Harm Principle

4. Is the intervention that has been refused of proven efficacy and therefore likely to prevent harm?
5. Does the intervention that has been refused by the parents not also place the patient at risk for serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?

Harm Principle

6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7. Can state intervention be generalized to other similar situations?

Harm Principle

8. Would most parents agree that state intervention was reasonable?

CantonRep.com
A Service of The Repository, Canton, OH

Boy who was subject of lawsuit dies

BY SHANE HOOVER
REPOSITORY STAFF WRITER

Noah Maxin

CANTON No one in the courtroom nearly five years ago wanted this day to come. Not Noah Maxin's parents. Not the doctors who said Greg and Theresa Maxin were gambling with their son's life by stopping chemotherapy.

Eleven-year-old Noah Maxin's funeral is today after losing his struggle with leukemia, a fight that included the court battle his parents won for the right to decide how to treat their son's disease.

In 2002, doctors diagnosed Noah with acute lymphoblastic leukemia. Abnormal white blood cells were gathering in his bone marrow, crowding out red blood cells, platelets and healthy white cells and leaving him at risk of infection, anemia and bleeding.

Noah began a treatment plan that included a blood transfusion, drugs and other measures. The cancer went into remission.

Noah's parents stopped the chemotherapy three months into a 3½-year plan favored by doctors at Akron Children's Hospital. The Maxins said they were concerned about the long-term effects of chemotherapy and wanted to treat Noah with a holistic approach that emphasized improved diet and strengthening the body's immune system. Another doctor took over his care.

Case of M

- 7 months old Amish girl with respiratory failure due to a large chest tumor
- The tumor is identified as a T cell lymphoma
- Treatment is 2 ½ years of chemotherapy
- 5 year cure rate is approximately 60%

Case of M

- M’s family asks that she not be treated with chemotherapy
- The oncology group agrees with the family and asks for an ethics consultation

Baby gets guardian

Ruling is step toward removing infant's life support

Lawyer recommends letting comatose infant 'die peacefully.' Judge weighs custody issue

By John Higgins
Beacon Journal staff writer

An Akron attorney recommended Thursday that a nearly 6-month-old infant with severe brain damage be withdrawn from all life support and be allowed to "die peacefully, painlessly and with dignity."

Summit County Probate Judge Bill Spicer will decide by early next week whether to authorize Ellen C. Kaforey to make such life and death decisions for the boy.

Aiden Stein has been in Akron Children's Hospital since March 15, when he was flown by helicopter from Mansfield after he stopped breathing while in his father's care.

Aiden

Hospital doctors have determined that most of Aiden's cerebral cortex has been irreversibly damaged and he will never be aware of his environment or his own being.

Please see **Infant, B4**

Father accused of beating girl resists removing life support

Akron Beacon Journal Friday, April 9, 2010

Case of D

- 13 year old young man with muscular dystrophy admitted with pneumonia and respiratory failure
- He has failed one attempt at being extubated
- Both he and his family request that if he fails extubation again, he not be re-intubated.

Adolescents and Medical Decision Making

- Treatment requires parental "consent" except in the following situations:
  - emergencies
  - emancipated minor
  - mature minor
  - statutory exemptions

Permission and Assent

- Children cannot "consent" to medical treatment
- Parents do not give consent for their children, they give permission
- Children should be given the opportunity to give assent for medical treatment when appropriate

Case of Baby J

- 9 weeks old Amish infant with apnea secondary to pertussis
- Parents refuse intubation and mechanical ventilation
- Physicians feel obliged to intubate the baby despite the parent’s wishes
- Ethics consultation requested emergently

Religious Objections To Treatment

- The parent’s right to freedom of religion does not take precedence over the child’s right to protection from harm
- Blood transfusion in the child of Jehovah’s Witnesses….”can not make a martyr of your child” (Prince vs. Massachusetts)
- Need to be sensitive to religious and cultural differences

Summary

- The standard for medical decision making in pediatrics is the best interest standard
- Parents are, in almost all cases, the ones to decide what is in the best interest of their child
- Implement strategies to prevent intractable disagreements
- Implement a process to address situations when intractable disagreements do occur
- Children need to be involved in these decisions to a degree which is appropriate for their level of development

"C'mon, c'mon—it's either one or the other."