



Treatment of terminally ill children: Ethics and Law

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Terminally ill children/patient

- Legal – in part
- Medical – prognostication
- Science – any?
- Key words: treatment, terminal illness, children





Predicting death in Children

- Recognize cure is no longer possible
- Focus on potentially achievable goals
- Children's hospice or palliative care: create transition, not abandonment
- Advanced directive regarding resuscitation
- Location of end of life care
- Saying good-byes
- Direct communication with parents and child
- Define expectations





Terminal illness

- **Terminal illness:** describes an active and progressive condition that cannot be cured or adequately treated and that is reasonably expected to result in the death of the patient
- Usually, a patient is considered terminally ill when life expectancy is estimated to be \leq six months, under the assumption that the disease will run its normal course
- Six-month standard - arbitrary
- Available estimates of longevity may be incorrect





Cases in the media

- 1976: Karen Ann Quinlan – parents sought to remove their daughter from ventilator
- 1990: Nancy Cruzan case, injured in automobile accident, 3 year court battle to have feeding tube removed
- 2005: Terri Shiavo, permanent vegetative state for 15 years





Questions

- What is treatment, what is care?
- What is information, and when is it adequate?
- How is consent manifested (expressed or implied)?
- Whose consent is needed?
- When, if ever, is involuntary treatment justified?
- What is the right to refuse treatment?
- When may a patient halt ongoing treatment?
- Advance directives and forgoing treatment





Terminally ill patients

- Each patient reacts differently to the news of carrying a terminal illness such as cancer
- Various stages of acceptance when a disease like cancer has been diagnosed
- The first stage is disbelief or denial . This first stage is usually short lived and usually lasts from a few days to a few weeks.
- The next stage is depression which is usually a reaction to the diagnosis





Treatment options: terminal illness

- Definition: no cure or adequate treatment for illness
- Accept some medical treatments: e.g. to reduce pain or decrease nausea etc
- Stop debilitating treatments , i.e. to reduce side effects
- Continue aggressive treatment , hope for a “miracle”
- Reject conventional medical treatment
- Seek unproven treatments
- Choices may change over time





Terminal illness

- Pediatricians reluctant to predict death
- Medical seniority and confidence in prognostication associated with greater accuracy¹
- Highly unusual cases disproportionately influence reluctance to predict dying
- Pediatric Index of Mortality (PIM, PIM2)
- Pediatric Risk of Mortality (PRISM, PRISM III)
- Provide population estimates, prone to errors



Treatment Options

- **Palliative care:** offered to terminally ill patients, regardless of their disease management, if it seems likely to help manage symptoms such as pain and improve quality of life.
- **Hospice care:** provided at home or in long-term care facility, provides emotional and spiritual support for the patient and loved ones.
- **Complementary medicine:** options such as relaxation therapy, massage and acupuncture may relieve some symptoms





Patient's rights vis à vis custodian

- Patient and Family: Cruzan v. Director, MDH, 497 U.S. 261 (1990) – clear and convincing evidence of patient's wishes
- Patient and State: Sell v. U.S., 539 U.S.166 (2003)
- Baby Doe cases and regulations
- Mrs. Schiavo – Florida





Standards: Jurisdictional variations

- Most state courts base right to refuse treatment on common law right to informed consent^{1,2}
- State courts rely on state constitutions, common law, state statutes for guidance³
- Right to die legislation: Federal, state

1. *In re Storar*, 52 N.Y. 2d 363, 438 N.Y.S. 2d 266, 420 N.E. 2d 64, 2. *Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E. 2d 417, 3. *Conservatorship of Drabick*, 200 Cal. App. 3d 185, 245 Cal. Rptr. 840

Oklahoma Hydration and Nutrition for Incompetent Patients Act - 1987

- **63 O.S. 3080.2(4)** defines incompetent patient as any person who is a **minor**, or who has been declared incompetent to make decisions affecting medical treatment or care, or in the reasonable judgement of the attending physician, is unable to make decisions affecting medical treatment or other health care services
- **Directs health care providers to provide hydration & nutrition to a degree that is sufficient to sustain life**
- Health care provider: not defined

Oklahoma Hydration and Nutrition for Incompetent Patients Act - Exceptions, 63 O.S. 3080.4

- 1. Attending physician of incompetent patient knows that the patient when competent, decided on the basis of information sufficient to constitute informed consent that artificially administered hydration or artificially administered nutrition should be withheld or withdrawn
- 2. Court finds by clear and convincing evidence that the patient when competent decided on the basis of information sufficient to constitute informed consent that artificially administered should be withheld or withdrawn

Oklahoma Hydration and Nutrition for Incompetent Patients Act - Exceptions

- 3. An Advance Directive has been executed
- 4. In the reasonable medical judgment of the incompetent patient's attending physician and a second consulting physician, artificially administered hydration or artificially administered nutrition will itself cause severe, intractable, and long-lasting pain to incompetent patient or such nutrition or hydration is not medically possible



Oklahoma Hydration and Nutrition for Incompetent Patients Act - Exceptions

- 5. In the reasonable medical judgment of the incompetent physician and a second physician:
 - a) the incompetent patient is chronically and irreversibly incompetent, b) the incompetent patient is in the final stage of terminal illness or injury, **and** c) the death of the incompetent patient is imminent



Oklahoma Hydration and Nutrition for Incompetent Patients Act - 1987

- “No guardian, public or private agency, court or any other person shall have the authority to make a decision on behalf of an incompetent patient to withhold or withdraw hydration or nutrition from said patient except in the circumstances and under the conditions specifically provided for in Section 3080.4 of this title”



Guardianship and Conservatorship Act; O.S. 3-119



- Limits powers of guardian
- “No guardian shall have the power to consent on behalf of the ward to the withholding or withdrawal of life sustaining procedures as defined by the Rights of the Terminally Ill or Persistently Unconscious Act from the ward ..”
- 3 exceptions: 1. guardian obtains specific authorization of the court, 2. guardian can enforce advance directive of ward, 3. guardian can enforce Do-Not-Resuscitate Order





Baby Doe Law & Medical Neglect

- Baby Doe Law: an amendment in 1984 to the Child Abuse Law; requires states receiving federal money for child abuse programs develop procedures to report medical neglect
- Defined as withholding treatment unless a baby is irreversibly comatose or the treatment is “virtually futile” in terms of survival
- Telephone hot lines set up to enforce legislation – intrusive without finding any actual abuse





Born-Alive Infant Protection Act (BAIPA)

- Passed in 2002
- Born Alive: defined as the complete expulsion of an infant at any stage of development that has a heart beat, pulsation of the umbilical cord, breath, or voluntary muscle movement, no matter if the umbilical cord has been cut or if the expulsion of the infant was natural, induced labor, cesarean section, or induced abortion

Pub. L. 107-207, 116 Stat. 926





The American Academy of Pediatrics (AAP)

- AAP: supports with-holding or withdrawing treatment when the projected burdens of the interventions outweigh the benefits to the child
- AAP: treatment decisions regarding an infant should be based on the judge-ment that the infant will derive net benefit
- AAP: Medical treatment that is judged to be harmful, of no benefit, or “futile” is inappropriate and should not be offered or provided¹

1. AAP, Committee on Fetus and Newborn, Non-initiation or withdrawal of intensive care for high risk newborns. *Pediatr.* 2007; 119(2): 401-403



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- Legal - partly
- Medical – prognostication mostly
- Science – is there any?
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Thank You!