

Refusals in Pediatrics

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Treatment Refusal

- Competent individuals have the right to accept or refuse any medical treatment, including life-saving medical treatment.
 - » This right is based on right to privacy, right to control one's own body, and right to personal autonomy.
- When individual lacks decision making capacity...
 - » Due to young age
 - » Due to mental retardation or mental illness
 - » Can be permanent or temporary
- What right does the surrogate have to refuse treatment?

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Surrogate Treatment Refusal

- Surrogate decision makers are held to a higher standard with regard to treatment refusal.
 - » Non-bonded guardians held to higher standard than bonded guardians.
- Surrogates are expected to make their decision based on
 - » Individual's advance directive
 - » Substituted judgment
 - » Best Interest
- Surrogate decisions are only overridden if:
 - » Decision is contrary to the stated preferences of the individual
 - » Decision is contrary to the child's best interest (usually only at the extremes of abuse and neglect)

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Causes of Refusal in Pediatrics

- Lack of mutual understanding
- Fear
- Denial
- Pain
- Cultural and religious beliefs of Individual
 - » (e.g., fear that it goes against God's will)
- Cultural and religious beliefs of community
 - » (e.g., fear of ostracism if one accepts a blood transfusion)
- Promises of alternate health care providers
- Lack of resources
- Secondary effects of the disease and its treatment.
 - » Disfigurement (e.g., amputation)
 - » Fear of side effects

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Refusals of Immunizations

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Case 1: Immunization Refusals

- Mr. T brings in his son Tommy for a pre-school physical exam. Tommy is 5 years old and will enter public school in September. Tommy recently moved from Ohio and has not received any immunizations. His parents base their refusal on religious grounds.
- FACTS: Most states respect religious refusals for immunizations unless there is an imminent public health threat.
- What do you do next?

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**Flanagan-Klygis, Sharp and Frader,
Dismissing the Family who Refuses Vaccines.
Arch Ped Adol Med 2005; 159: 929-934.**

- 1003 pediatricians from the American Academy of Pediatrics
 - » 452 returned surveys (45%)
- 256 of 302 (85%) pediatricians reported encountering partial vaccine refusal during the preceding 12 months.
 - » 162 of 302 (54%) reported encountering a parent who refused all vaccines.
- Reasons for refusals:
 - » Safety concerns
 - » Too many at one time
 - » Philosophical or religious objections

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Physician Response

- For parents refusing specific vaccines, 82 (28%) would ask the family to seek care elsewhere.
- For parents refusing all vaccines, 116 (39%) would refer the family
- Reasons:
 - » Lack of shared goals
 - » Lack of trust
 - » Fear of litigation
- Some said the type of vaccine refusal was extremely important.
 - » DTAP, HIB, MMR and IPV were more important than Pneumococcal, Hep B and Varicella-zoster vaccine.

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Diekema & the Committee on Bioethics, Responding to Parental Refusals of Immunization of Children.

Ped 2005; 115: 1428-1431.

- Cited other data: 7 of 10 pediatricians reported they had a parent refuse an immunization in the 12 months prior to the survey.
 - » Usually MMR (fear of autism)
 - » Also refused Varicella, then pneumococcal, Hep B
- 4% of pediatricians refused permission for an immunization for their own children younger than 11 years.
- Small percentage said they always (4.8%) or sometimes (18.1%) tell parents they will no longer serve as the child's physician.

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AAP Committee on Bioethics

- First response of most pediatricians
 - » Attempt to educate
 - » Document
- Consider 3 types of cases
 - » Cases in which refusal risks harming the child sufficiently that the decision constitutes medical neglect and justifies DCFS involvement.
 - (Refusal of tetanus after sustaining a deep and contaminated puncture wound.
 - » Cases in which refusals put other children at risk of harm sufficient to justify public health intervention
 - Immunization requirements for school entry.
 - » All other cases...

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AAP Response to Parental Refusals

- Listen carefully and respectfully to parents' concerns recognizing that parents may not use the same decision criteria and may weigh evidence differently.
- Educate
 - » Risks of encephalopathy from measles vaccine is 1 in 1 million
 - Risk of encephalopathy from measles disease is 1000X greater.
- Negotiate (some parents want to delay MMR until 3 years because of fear of autism)
- Continued refusal after adequate discussion should be respected unless the child is put at significant risk of harm (e.g., during an epidemic).
- In general, pediatricians should avoid terminating the relationship.
 - » This allows for continued discussion
 - » Child still needs and deserves access to medical care for other health problems.

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Case 2: Immunization Refusals

- Mrs. V. brings in her daughter Violet who is 7 years old. Violet has been home-schooled and Mrs. V. has avoided all immunizations because she wanted her daughter to be part of the decision making process. Violet has agreed to at most two needles today.
- Questions
 - 1) Should you work with this family?
 - 2) Can you work with this family?
 - 3) What questions about Violet and the family do you want to ask?
 - 4) What immunization(s) do you recommend?

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Case 2: Which Immunizations?


- AGE:
 - » At age 7 years, HIB and PREVNAR are less necessary (risk highest in younger children).
 - » Hepatitis B vaccine can surely wait until the child is a teenager.
- TRAVEL/foreign exposure
 - » If the family lives in the US and does not plan to travel outside of the US, and does not have an international nanny, one can wait on the IPV.
 - » If one is not planning to go on a camping trip, Tetanus can be safely withheld.
- Health of Family members
 - » If a household member has severe COPD or asthma, thought should be given to influenza.

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Case 2: Which Immunizations?

- Which immunizations would I choose for a healthy 7 year old child, unremarkable risks and exposures (in order of importance)?
 - » MMR
 - » DPT
 - Want to complete a series. Second dose can be as soon as one month; as long as years...(in contrast with Hepatitis A that must be completed in one year, for example).

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Refusals of Diagnostic Testing and Screening

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Case 3: Refusal of Newborn Blood Screening for Metabolic Diseases

- Ms F delivered Frances, a healthy full-term infant, twenty-four hours ago. She refused vitamin K and Hepatitis B because she did not want to put Frances through any more discomfort than the birth process. You come to draw the newborn metabolic screening prior to discharge but she refuses. She agrees to reconsider and will take the card to her private pediatrician who she plans to see in two days. You suspect that she will again refuse newborn metabolic screening. How should you respond?
- FACT: Newborn screening for a variety of treatable conditions are mandatory in 49 of the 50 states. This means screening can be done without parental consent.
- FACT: In virtually all states, parents have the right to refuse screening based on religious objections and sometimes based on philosophical objections. Most clinicians and parents are unaware of this.

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Case 3: Newborn Screening

- Depending on the number of conditions, the risk that a child from a non-high-risk family has any of the condition ranges from 1/3000 to 1/>100,000.
- Some conditions place the child at imminent risk of morbidity and mortality; others can be diagnosed clinically at a later stage “relatively safely”.
- Are the risks high enough to justify third-party intervention?

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Case 4: Refusal of Work-Up in the Emergency Room

- Ms L brings her 3 week old to the emergency room because her pediatrician had told her to bring her child in to be seen immediately if he had a fever. The baby has a cold as does Ms L and the infant's 2 year old sister. Both Ms L and the 2 year old also had a fever 2 days ago. Ms L is breast feeding and states that the baby is eating and sleeping well.
- The doctors explain that this scenario requires a “sepsis work-up” and admission. Ms L refuses the spinal tap and refuses admission.
- What do you do next?

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Case 4: Sepsis Work-up Refusal

- Is this child abuse or neglect?
- FACT: Standard of Care is to do full sepsis work-up and admit.
- FACT: Some children are treated as outpatients and there are data to show it can be done when certain parameters are met and good follow-up is assured.

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Refusals of “Standard of Care” Medical Treatment

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Case 5: Chad Green

- 2 ½ year old boy diagnosed with leukemia in 1977.
- Given 50-75% chance of 5 year survival with chemotherapy.
- Parents initially accepted chemotherapy, but then decided to use Laetrile and metabolic therapy rather than chemotherapy based on religious beliefs.
- Massachusetts quickly declared Chad a ward of the state, removed from physical custody, and began chemotherapy.
- Over one year parents regained physical but not medical custody.

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Case 5: Chad Green 1977-1979

- Upon regaining custody, family ran away to Mexico to get Laetrile.
- Chad died suddenly in 1979 (suspected cause: cyanide toxicity from his treatment).
- His refusal played out on National TV.



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Asser and Swan, Child Fatalities from Religion-Motivated Medical Neglect.

Pediatr 1998; 101: 625-629.

- Reviewed 201 cases of potential child fatality in faith-healing sects between 1975-1995.
 - » In 14 cases, lack of sufficient information to be certain of cause of death
 - » In 15 cases, it could not be established that exclusive reliance on faith healing contributed to the demise.
 - » 172 cases of child fatality in faith-healing sects.
 - 113 died after neonatal period
 - 59 died during prenatal and perinatal period

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Child's Expected Outcome with Treatment

- 113 children who died after the neonatal period.
 - » 15 with cancer
 - Available medical care would have given them a reasonable chance for long-term survival and reduction of pain and suffering.
 - » 98 did not have cancer
 - 92 had an excellent prognosis with commonly available medical and surgical care
 - 4 had a good prognosis
 - 2 would NOT have clearly benefited from clinical medical care.

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Perinatal and Prenatal Deaths

- 59 died during prenatal and perinatal period
- All but one of the newborns would have had a good to excellent expected outcome
 - » The one child had anencephaly & myelomeningocele
- Complications were often during labor and delivery and were out of hospital deliveries.
 - » 6 women died from complications of the delivery.

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Policy Regarding Religious Refusals

- 1974, US Dept of HEW (now HHS) required states receiving federal child abuse prevention and treatment grants to have religious exemption to child abuse and neglect statutes.
 - » Within a decade, virtually every state had these exemptions in the juvenile code, criminal code or both.
- In 1983, federal government removed religious exemptions from federal mandate.
 - » Today 5 states have no exemptions.
 - » (Difficult to overturn policies)
- 1988, American Academy of Pediatrics called for the elimination of religious exemption laws
 - » 26% of the deaths in Asser and Swan's study occurred after 1988.

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American Academy of Pediatrics, Committee on Bioethics, Religious Objections to Medical Care.
Pediatr 1997; 99: 279-281.

- The American Academy of Pediatrics (AAP) believes that all children deserve effective medical treatment that is likely to prevent substantial harm or suffering or death.
- The AAP advocates that all legal interventions apply equally whenever children are endangered or harmed, without exemptions based on parental religious beliefs.
- To these ends, the AAP calls for the repeal of religious exemption laws and supports additional efforts to educate the public about the medical needs of children.

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Case 6: Joseph Hofbauer

- 8 year old with Hodgkin's disease diagnosed June 1978.
- When New York State authorities attempted to place him in protective custody, his parents filed suit.
- Parents convinced family court judge Loren Brown to rule against recognized treatment of Hodgkin's disease. Brown stated that "This court also finds that metabolic therapy has a place in our society, and hopefully, its proponents are on the first rung of a ladder that will rid us of all forms of cancer."
- In part, Brown found in favor of parents because parents had placed their child under the care of a licensed physician.

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Case 6: Joseph Hofbauer 1970-1980

- On appeal, New York State Supreme Court Judge Michael Sweeny noted that the critical issue was whether his parents had supplied him with ADEQUATE medical care given the seriousness of his condition.
- Sweeny was convinced because parents and physician stated they would accept conventional therapy if Joseph began to deteriorate.
- Joseph died of his cancer 2 years later.

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When the Pediatrician Goes to Court

Court-Mediated Disputes Between Physicians
and Families over the Medical Care of
Children by Derry Ridgway. *Arch Pediatr
Adolesc Med* 2005; 15: 891-896.

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When the Pediatrician Goes to Court

- American Academy of Pediatrics takes the position that physicians are obliged to seek legal recourse when parental refusal places a child at clear and substantial risk.
- In setting of urgently needed care, mechanisms are in place to make a prompt and enforceable transfer of medical decision authority from parents to a designated surrogate.

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Published Court Opinions

- 65 judicial opinions from 50 identified disputes between 1912-1998.
- Impossible to count or characterize the know the legal relevant decisions that are not accompanied by published opinions so it is not known how representative these 50 cases are.

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Summary of Case Characteristics-1

- 50 disputes involving 66 children
- Gender
 - » Males 31; Females 25; gender unknown 10
- Patient age
 - » 14 children less than 1 year
 - » 23 children between 1-12 years
 - » 19 children between 12-18 years
 - » 10 children age not stated
- 14 in New York; 14 in Washington; 4 California and 4 in Florida. Rest in 16 other states (1-3)

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Summary of Case Characteristics-2

- Medical Care in Dispute
 - » 12 patients (12 disputes) involved cancer
 - » 26 patients (17 disputes) involved surgery
 - » 26 patients (17 disputes) involved transfusion
 - » 6 patients (4 disputes) involved infection
 - » 3 patients (3 disputes) involved behavior
- 30 disputes involved religious objection; 20 disputes involved other objection.
- Most of the disputes 1970 and beyond
- Rise in number of cancer cases since 1970.

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Court Decisions

- 44 disputes (88%) were initially decided in favor of the physicians
 - » 24 decided in emergency hearings
- 37 of the 44 were reviewed
 - » 31 affirmed (in favor of physicians)
 - » 6 Reversed (Parental refusal Permitted)
- 5 of the 6 favoring parental refusal of care were reviewed.
 - » 3 affirmed (Parental refusal UPHELD)
 - » 2 reversed (in favor of physicians)

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Court Decisions

- Overall 80% of cases favored physicians.
 - » Did not change across time and was not affected by patient characteristics (age, sex, or disease).
- Physicians more likely to succeed against religious objections [27 of 30 or 90%] versus [13 of 20 or 65%]
 - » Religious cases can cite Prince v Massachusetts where parents CANNOT make martyrs of their children.
- Patient outcome is known for only 11 of the 66 children.
 - » 7 died; 4 survived.

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Undesirable Consequences

- Because of the time it takes, the child's medical status or other circumstances changed during the period of judicial intervention, rendering court-authorized interventions inappropriate.
- Compromise family's privacy and integrity.

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Case 7: In re E.G.

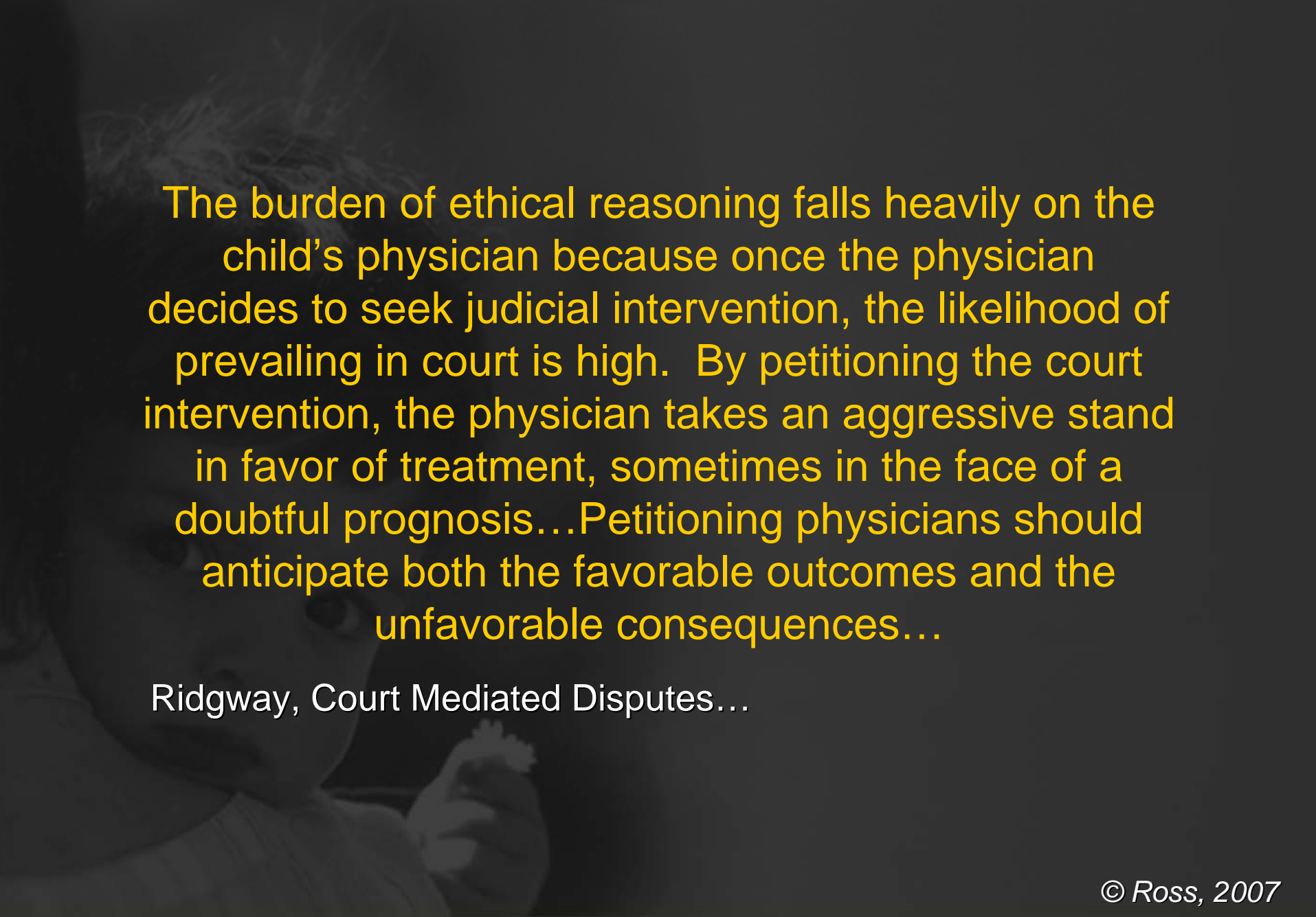
- In February 1987, EG, a 17-year-old adolescent was admitted to the University of Chicago hospital and diagnosed as having acute leukemia. While the adolescent and her parents agreed to treatment for the leukemia, she and her parents stated that they were Jehovah's Witnesses and refused blood products.
- If you were the physician what would you do?
 - 1) Give chemo (Her hemoglobin is 4) without blood (which may kill her)**
 - 2) Give chemo and blood (under court-order)**
 - 3) Provide palliation only (chemo only as a package-deal)**
 - 4) Transfer her care to a physician willing to respect her religious beliefs.**

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Case 7: In re E.G.

- While court proceedings occurred, physicians did take emergency medical custody of E.G. She was given blood transfusions.
- IL Court concluded that E.G. was a mature minor and could have refused blood products.
- If you were the physician what would you do?
 - 1) Give chemo (Her hemoglobin is 4) without blood (which may kill her)**
 - 2) Give chemo and blood (under court-order)**
 - 3) Provide palliation only (chemo only as a package-deal)**
 - 4) Transfer her care to a physician willing to respect her religious beliefs.**

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The burden of ethical reasoning falls heavily on the child's physician because once the physician decides to seek judicial intervention, the likelihood of prevailing in court is high. By petitioning the court intervention, the physician takes an aggressive stand in favor of treatment, sometimes in the face of a doubtful prognosis...Petitioning physicians should anticipate both the favorable outcomes and the unfavorable consequences...

Ridgway, Court Mediated Disputes...

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Case 8: Billy Best

- In June 1994 Billy Best, at 16 years old, was diagnosed with Hodgkin's disease. He began chemotherapy the following month at Dana Farber Cancer Center in Boston, but after 5 sessions, he lost 20 pounds and his hair.
- He observed his aunt die after the chemotherapy made her sick, and he too felt the chemo was killing him.
- He told his parents he wanted to stop the chemo, but they urged him to continue the treatments.
- Questions:
 - » If parents and adolescents disagree, whose wishes should be respected?
 - » Or should the arbitration depend on which decision each party holds (whether to accept or refuse chemotherapy).
- Treatment continued.

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Case 8: Billy Best

- A Born-Again Christian, Billy packed his skateboard and \$300 into a small duffle bag, left home, and put his life in God's hands. He fled to Houston where he met other skateboarder enthusiasts.
 - » Does the fact that Billy was willing to run away change your answers about how the physicians should respond to his refusal?
- After he ran away, his parents begged him to come home, and promised not to force more chemotherapy on him.
 - » Billy returned to Boston.
- Question:
 - » Now that Billy and parents agree against treatment, what should the physicians do?
- Physicians reported family to the Department of Social Services which tried to have Billy removed from his parents' custody.
- State of Massachusetts dismissed the case after intense media coverage of the case.

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Case 8: Billy Best (Postscript)

- In January 1995, the family visited Gaston Naessen in Quebec. Billy began daily injections of Mr. Naessen's nontoxic 714-X therapy. Billy made nutritional changes, including avoiding red meat, dairy products, sugar, and carbonated beverages; he added fresh, organic produce and distilled water to his diet and began taking vitamins, minerals, and Essiac herbal tea.
- March 1995, CAT scan revealed no evidence of tumor.
- March 2005, Billy is a healthy young adult (advocating for alternative medicines) and is a construction worker.
- QUESTION: Does the fact that Billy has beaten the odds change your decision?

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American Academy of Pediatrics, Committee on Children with Disabilities, Counseling Families Who Choose Complementary and Alternative Medicine for Their Child With Chronic Illness or Disability. *Pediatr* 2001; 107: 598-601 (reaffirmed May 2005)

- Use of complementary and alternative medicines [CAM] by at least one-third of adults.
- Numbers in pediatrics unknown, but common and increasing.

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Physician Response to CAM

- Seek information for yourself and be prepared to share it with families.
- Evaluate the scientific merits of specific therapeutic approaches.
- Identify risks or potential harmful effects.
- Provide families with information on a range of treatment options (avoid therapeutic nihilism).
- Educate families to evaluate information about all treatment approaches.
- Avoid dismissal of CAM in ways that communicate a lack of sensitivity or concern for the family's perspective.
- Recognize feeling threatened and guard against becoming defensive.
- If the CAM approach is endorsed, offer to assist in monitoring and evaluating the response.
- Actively listen to the family and the child with chronic illness.

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How to Respond to Refusals

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Refusals in Pediatrics

- Can occur at all stages
 - » ...diagnostic tests such as newborn metabolic screening (low probability) or sepsis work-up
 - » ...treatment refusals such as immunizations (prevention) and blood transfusions and chemotherapy (life-saving treatments)
- Not all refusals are the same
 - » Variability in degree of harm
 - » Variability in likelihood of harm
 - » Variability in the role of the child

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10 Step Approach to Refusals

1. Ensure good communication
2. Make use of interpretation services and other professionals (social workers, clergy, etc) and parent support groups to ensure open communication and opportunities to understand parental perspective.
3. Offer to include additional family members (esp. because in some cultures and families, people other than the parents may be regarded as the true decision makers)

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10 Step Approach to Refusals

4. Consider the possibilities of accommodating the family's preferences. Sharing management with alternative or complementary medicine when safe to do so.
5. Consider the need for ensuring the child's voice is heard and determining the child's level of decision-making capacity.
6. Reassess the seriousness of the consequences of various options for the child's current and future well-being, taking into account the fullest possible understanding of the child's situation and interests.
7. Consider a second opinion

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10 Step Approach to Refusals

8. Consider whether there are features of the child's situation (including the family's views and the practical context) which may mean that a medically less-preferable treatment regimen is overall better for the child.
9. If conflict remains unresolved at this stage, Ethics consult.
10. If conflict remains unresolved, consider legal involvement. Whether to involve courts (state) and at what point should depend in part on the urgency and seriousness of the need for treatment. Best as a last resort.

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Concluding Remarks: How to Respond to Refusals in Pediatrics

- Remember that parents want to do what is best for their children.
 - » There may be exceptions.
 - » There may be exceptional situations.
- Remember that many medical decisions incorporate value judgments.
- Remember that many medical decisions are based on probabilities.

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