

Session 5. Religious, Cultural, and Philosophical Objections to Care

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Overview

Responding to a parent's refusal of medical care based on religious, cultural, or ethical considerations presents complex challenges. Physicians must balance respect for the parent's wishes and legal rights with the child's well-being. What are the limitations on a parent's right to refuse treatment for a child? What are the steps a physician must take to justify involving state agencies to compel treatment? How does a physician resolve conflicts between the parent's values and those of the medical profession?

This module will explore the ethical issues that arise when the values of parents and health care professionals come into conflict over health care decisions. Participants will learn the components of informed consent or permission and understand the limitations of a parent's right to refuse treatment for a child. Participants will discuss the steps necessary to justify involving state agencies to compel treatment for a child and identify strategies to resolve conflicts between the values of a parent and the medical profession.

Instructor's Guide

- Case Summary
- Alternative Cases
- Learning Objectives
- Suggested Reading for Instructor
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Case Summary

A 4-year-old presents to the emergency department with a 3-cm laceration sustained while walking in a friend's backyard. The wound is moderately dirty. The child's mother agrees to have the wound irrigated and sutured. She says she believes in naturopathy and will not permit antibiotics or immunizations. The child has had no tetanus immunizations.

- Is this a decision that you will permit the mother to make?
- How do we decide when it may be necessary to interfere with a parental decision?
- If you decide that a parental decision places a child in danger, what are your options?
- Under what conditions would you feel compelled to call child protective services or obtain a court order to compel treatment?

- Does it matter if the basis for the parental decision is religious, cultural, or something else?

Alternative Cases

1. A 5-year-old child receives a diagnosis of acute lymphocytic leukemia and requires chemotherapy that will necessitate periodic blood transfusions. His parents belong to the Jehovah's Witness faith and consent to treatment of the child's cancer but firmly refuse to consent to any blood product transfusions.
2. A 5-year-old Hmong child has a cleft palate causing severe speech impairment. The family refuses surgical repair. The pediatrician considers this neglect and wonders whether she should involve child protective services or seek a court order to compel treatment. (Should cultural differences be respected in decisions about health care for children? Is this different from a Christian Scientist refusing treatment for meningitis or a Jehovah's Witness refusing a life-saving blood transfusion?)

Learning Objectives

1. Understand the components of informed consent or permission.
2. Understand the limitations of a parent's right to refuse treatment for a child.
3. Identify the steps one must take to justify involving state agencies to compel treatment of a child.
4. Recognize the conflict between the parent's values and those brought to the situation by medical professionals and identify strategies for resolving this conflict.

Suggested Reading for Instructor

American Academy of Pediatrics, Committee on Bioethics. Policy statement: Informed consent in decision-making in pediatric practice. *Pediatrics*. 2016;138(2): e20161484

American Academy of Pediatrics, Committee on Bioethics. Policy statement: Conflicts between religious or spiritual beliefs and pediatric care: informed refusal, exemptions, and public funding. *Pediatrics* 2013;132(5):962-965

Katz AL, Webb SA; American Academy of Pediatrics, Committee on Bioethics. Technical report: Informed consent in decision-making in pediatric practice. *Pediatrics*. 2016;138(2):e20161485

Further Reading

Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004;25(4):243–264

Diekema DS. Revisiting the best interest standard: uses and misuses. *J Clin Ethics*. 2011;22(2):128-133

Diekema DS. Religious objections to medical care. In: Jennings B, Eckenwiler L, Kaebnick G, et al, eds. *Bioethics*. 4th ed. Farmington Hills, MI: MacMillan Reference USA; 2014:2713-2717

Sheldon M. Ethical issues in the forced transfusion of Jehovah's Witness children. *J Emerg Med*. 1996;14(2):251-257

Case Discussion

What do you think is best for the patient?

This patient has sustained a wound that you would consider dirty and at risk of tetanus. Usually, this would result in a recommendation for administration of tetanus vaccine and immunoglobulin. Given the contamination of the wound, you would also recommend antibiotics. The child's mother declines all of those treatments because of her naturopathic beliefs. Should she be allowed to make that decision?

Emphasize that simply having established what you think is best for the patient does not establish that a parent who disagrees with you should have her refusal of treatment overridden. The first question is about what you think is best for the child. The second question is about what authority you have to interfere with the choice of a parent.

What is your authority in this situation?

Except in emergency situations in which a child's life is threatened imminently or a delay would result in significant suffering or risk to the child, a physician cannot do something to a child without the permission of the child's parent or guardian. Touching (or administering a medication or vaccine) without a legally valid consent is considered battery under the law.

Assuming you have not been successful in changing the mother's mind, what are your options?

Although parents are given wide latitude in terms of the decisions they make on behalf of their children, parental authority is not absolute, and when a parent acts contrary to the best interest of a child, the parent's authority to make decisions can be limited. However, only the state can order a parent to comply with medical recommendations. The physician's options include tolerating the parent's decision (while continuing to try to convince her to act otherwise) or involving a state agency. This can take different forms but most frequently includes involvement of the state child protection agency (ie, making a claim of medical neglect) or a court order. Both of these will generally be perceived as adversarial by parents and may permanently alter the physician's relationship with the family.

How do we decide whether a parent has exceeded her authority in making a medical decision for her child? What are the limits of parental authority to refuse a medical intervention? In other words, what is the threshold for when we should involve state agencies in a case like this?

When a parent's decision places a child at *significant* risk of *serious* harm, the parent has exceeded her authority.

How much risk is too much for a child to be subjected to by a parent? Does it matter how great the potential harm is?

Harm must be more than trivial. Generally, harm must be serious. The harm in this case is the risk of tetanus, which nearly every reasonable person would consider to be a serious consequence.

Does it matter how likely the harm is?

Risk of harm must be significant, not simply a possibility. It is easier to justify a claim that the risk of refusing tetanus vaccination and immunoglobulin is significant when an unvaccinated child has sustained a deep grossly contaminated wound as opposed to a cut with a clean kitchen knife.

Does it matter how imminent the harm is?

In this case, the harm is not imminent in the sense that something needs to be done immediately. But there is a time beyond which immunization and immunoglobulin administration would no longer be effective in preventing tetanus. Thus, in this case, we have a day or two to try to work with this family, but not much more than that.

Does it matter whether the recommended treatment is accompanied by the potential for significant toxicity or side effects or risks?

It does matter, because it is the overall balance between harm and risk of the proposed intervention that must be considered. If a treatment is accompanied by significant risk of serious harm, the threshold for seeking state power to administer the treatment against parental wishes becomes higher and requires a higher likelihood that the intervention will result in an important benefit to the child.

Compelling any treatment should also require that the physician demonstrate evidence that it is likely to benefit the child. There is an important difference between proven efficacy (data-based) and convention ("it is the standard of care") when one is attempting to convince parents to accept an intervention.

The usual ethical concepts of harm, benefit, and best interest are value-laden. What seems to be minimal harm to many medical professionals may seem like a huge harm to those with different belief systems. What counts as significant is very personal.

Judgments in medicine about efficacious care are often based on minimal data and can change with time. Evidence-based standards of likelihood of benefit should be required to override a parent's assessment of what would be best for the child.

Would it matter if the parents were Christian Scientists and they were refusing immunization, immunoglobulin, and antibiotics because consent would violate their religious belief (in contrast with a nonreligious belief like naturopathy)?

The constitution requires that the government not interfere with religious practice or endorse particular religions. The government also has an interest in protecting children and innocent third parties.

The constitutional right to religious freedom does not extend to practices that are likely to harm a child. In *Prince v Williams*, the US Supreme Court stated, “Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”

Although the constitution does not appear to allow parents to martyr their children for religious beliefs, it is important to recognize that our reasons for interfering with parental decision-making are not because the parents have a religious belief, but because their decision places a child at substantial risk of serious harm. That standard remains the same whether the parents’ reason for refusing an intervention arises from religion, culture, or some other source.¹

In the case of routine vaccination, the American Academy of Pediatrics does not believe parental refusal should be viewed as child neglect.² However, under conditions in which the level of risk from being unvaccinated rises to dangerous, such a refusal could be considered medical neglect. The example provided by this case—a grossly contaminated deep wound—might be such a case with regard to the tetanus vaccine.

Are there other important considerations? Is there a series of questions physicians should ask to help decide whether they should seek state action to overturn parental refusal of a recommended medical intervention?

Conditions for justified state interference with parental decision-making include³:

1. By refusing to consent, are the parents placing their child at significant risk of serious harm?
2. Is the harm imminent, requiring immediate action to prevent it?
3. Is the intervention that has been refused necessary to prevent the serious harm?
4. Is the intervention that has been refused of proven efficacy and therefore likely to prevent the harm?
5. Does the recommended medical intervention provide a significantly more favorable benefit/burden profile than the option chosen by the parents?
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 the state intervention be generalized to similar situations involving other parents?

8. Would most people agree that the state intervention was reasonable in order to protect the child?

Conclusions and Suggestions

Remember that parents who disagree with their physician believe they are doing what is best for their child.

It is important to maintain an atmosphere of respect and concern for the child in disagreements with parents. Respectful persuasion is far preferable to attempts at coercion.

Attempting to interfere with a parental decision is not appropriate if prognosis is grave even with treatment or if the treatment in question is not clearly efficacious and beneficial.

References

1. Diekema DS. Religious objections to medical care. In: Jennings B, Eckenwiler L, Kaebnick G, et al, eds. *Bioethics*. 4th ed. Farmington Hills, MI: MacMillan Reference USA; 2014:2713-2717
2. American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314–317
3. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004;25(4):243–264

This instructor's guide is part of a collection edited by Douglas S. Diekema, MD, MPH, FAAP; Steven R. Leuthner, MD, MA FAAP; Felipe E. Vizcarrondo, MD, MA, FAAP on behalf of the American Academy of Pediatrics Committee on Bioethics and Section on Bioethics.

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