

Session 2. Autonomy, Beneficence, and the Rights of Parents and Children: Exploring the Application of Ethical Principles in Pediatrics

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Overview

Participants will discuss the application of widely accepted principles of medical ethics in pediatrics, which involves the unique physician-patient-parent relationship. Medical decisions are best made with the rights and obligations of each of these individuals kept in mind, as well as an understanding of ethical principles. The following cases explore the ethical principles of autonomy and beneficence, the patient's best interest standard, and the rights of parents, children, and adolescents in medical decision making. Each case is discussed in light of relevant policies and guidelines of the American Academy of Pediatrics (AAP). Participants will review these ethical principles as well as understand a practical approach to applying them to future cases. Participants should be made aware that an approach to ethical problems based on relevant rights and principles may be helpful, but this is not the only available approach, and other approaches may also be valid and prove useful.

Instructors Guide

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

You are the physician taking care of a 4-year-old girl admitted to the pediatric intensive care unit 3 days ago after prolonged submersion in a neighbor's pool. She has been on mechanical ventilation since admission and remains critically ill. According to the clinical team, survival is uncertain yet possible, but with a high likelihood of neurological disability. The parents request continuation of life-sustaining medical treatment, such as mechanical ventilation and medically administered nutrition and hydration, and extensive resuscitation, including chest compressions and epinephrine, in the event of cardiac arrest.

- Who should decide on the medical treatment plan?
- What approach best serves the interests of the child?
- What are the relevant rights of the child in this setting?
- What are the relevant rights of the parent(s)?
- What would you do? Would you offer withdrawal of life-sustaining medical treatment? Would it be appropriate to withdraw without parental permission?

Alternative Cases

1. A 14-year-old girl is brought into the office by her mother because of a suspicious-looking mass on her neck. The girl refuses testing of any sort, including even venipuncture, but the mother insists that you perform a biopsy right now in the office to determine the cause.
2. The parents of a male infant born earlier this morning at 27 weeks' gestation via emergency cesarean section have just informed you that they would like to withdraw life-sustaining medical treatment, including mechanical ventilation and intravenous nutrition/hydration, for their child, stating that they do not want to care for "a handicapped child."
3. You are the pediatrician taking care of a 3-day-old female infant in the well-baby nursery. She is ready to be discharged home, but you are concerned about possible congenital heart disease after hearing a harsh murmur on auscultation today. The parents have refused imaging and invasive diagnostic testing to investigate the cause of the murmur, saying she will be fine, and will outgrow this murmur as her older brother did.
4. An 8-year-old boy and his parents are seeing you in the office for disruptive behavior, both in the classroom and at home, that is concerning for attention-deficit/hyperactivity disorder. Both parents have demanded psychotropic drugs, while the boy is sitting alone on the examination table, refusing to take medication, repeating "I don't want to take anything."

Learning Objectives

1. Review and understand the ethical principles of autonomy and beneficence.
2. Understand the patient's best interest standard.
3. Recognize that parental authority does not equate to "parental autonomy."
4. Understand the rights of the child and their parents.
5. Differentiate between permission, assent, and consent.
6. Understand how to apply these ethical principles to future cases.

Suggested Reading for Instructors

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

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

American Academy of Pediatrics, Committee on Child Abuse and Neglect and Committee on Bioethics. Forgoing life-sustaining medical treatment in abused children. *Pediatrics*. 2000;106(5):1151–1153

Further Reading

Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 6th ed. New York, NY: Oxford University Press; 2009:99, 114, 138, 207, 371, 65

Cummings CL, Mercurio MR. Ethics for the pediatrician: autonomy, beneficence, and rights. *Pediatr Rev*. 2010;31(6):252–255

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Hardwig J. *Is There a Duty to Die? And Other Essays in Medical Ethics*. New York, NY: Routledge; 2000

Prince v The Commonwealth of Massachusetts, 321 US 158 (1944)

American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314-317

Case Discussion

What are some rights of the child relevant to medical management decisions?

The child has a right to life, which includes a right to treatment that has a reasonable chance of resulting in a significant extension of life. She also has a right to mercy, here defined as the right not to be made to experience unnecessary suffering. This would include pain that results from treatment that offers no significant benefit to her. She has a right to justice, here defined as fair and equal medical treatment.^{1,2} Although not relevant to this case, it should also be noted that a child has a right to be informed and to participate in the decision making as appropriate for age and mental state.

What are some rights of parents relevant to medical management decisions?

Parents have a broad but not unlimited right to make decisions on behalf of their children as they see fit. They have a right to guidance and support from the medical team as they make those decisions and to have explained to them all relevant information so that their decisions are well informed.^{1,2}

As described previously, when the patient is a newborn, an infant, or a child, parents are generally accorded the right to make medical decisions on the child's behalf, referred to as parental authority. Contemporary justifications for parental authority have included (1) parents are responsible for bringing up their children, and that responsibility necessarily requires having rights for decision-making; (2) apart from the child, parents will be the ones most likely to have to live with the consequences of any decisions made; (3) parents know the child best; and (4) affection and close family ties makes parents most likely to reach decisions based on the child's best interest.³

Parental authority, although widely accepted, is not absolute. For example, although a competent adult has the right to refuse even lifesaving medical treatment for herself, she is generally not accorded the right to do so for her child. Examples might include requiring chemotherapy for a child with a highly treatable cancer despite parental insistence on herbal or complementary medicine alone, or requiring blood products for a child with hemophilia whose parents decline on religious grounds. As expressed by the US Supreme Court, "Parents are free to become martyrs themselves. But it does not follow that 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."⁴

What is autonomy?

The word autonomy derives from the Greek *autos* (self) and *nomos* (rule). Respect for autonomy, central to adult medical ethics, implies recognizing one's right to make decisions for oneself and act on these freely.¹ This right has been understood in the context of health care to include a right to make decisions based on accurate and complete information. Competent patients, or more precisely those with capacity, are generally accorded a right to autonomy or self-determination. Perhaps the most fundamental component of this right is the right to refuse unwanted therapy. This does not necessarily include a right to demand any therapy.

Capacity in this context can be defined as having the ability to understand a proposed therapy or procedure, to understand its risks, benefits and alternatives, and to be able to then arrive at a decision based on consideration of these factors in light of one's values and life plans.¹ An autonomous decision is one made with adequate information and understanding of the implications of various possible outcomes. For any patient not considered to possess capacity, a truly autonomous decision is not possible, so a surrogate decision maker should speak and decide on that patient's behalf. In the case of young children, parents nearly always fill the role of surrogate decision maker.²

Adolescents may have the capacity to make certain medical decisions and are understood to have developing autonomy.

The doctrine of informed consent, which requires that patients with capacity be given the relevant diagnostic and prognostic information and then retain the right to grant or withhold consent for any treatment, is derived from the principle of respect for autonomy.

What is the difference between parental informed consent, permission, and patient assent? Why is this important?

The doctrine of informed consent is limited in pediatrics, in that only patients *themselves* can actually give informed consent. Parents or other surrogate decision makers provide *informed permission* for diagnostic procedures and medical treatment for their children.^{5,6} The AAP also endorses the concept of *assent*, the developmentally appropriate child's willingness or preference to participate in a proposed therapy, procedure, or research. The practice of soliciting assent is modeled after obtaining informed consent from competent adults and recognizes the child's developing ability to participate in the decision-making process. Soliciting assent also indicates an expectation that children will be active participants in their health care. Physicians can foster this practice by:

1. Helping the child achieve a developmentally appropriate awareness of the condition;
2. Telling the child what to expect with tests and treatment;
3. Assessing the child's understanding of the situation; and
4. Soliciting an expression of the child's willingness to accept the proposed care.^{5,6}

It may not always be possible to include children in the decision-making process due to age or mental condition, as in this case, but this may be possible and is encouraged in many other situations.

What is beneficence?

The principle of *beneficence* underscores the moral obligation to act for the benefit of others (here, patients), including protecting the rights of others, preventing harm to others, and helping those in danger.¹ One can see that respect for autonomy and beneficence may at times be in conflict, such as when a competent patient refuses a treatment that would clearly benefit him or her.

On which principles should surrogate medical decisions be based?

When deciding on behalf of an incompetent patient, decisions are ideally based on the patient's previously expressed wishes or what the surrogate decision maker believes the patient would have wanted, known as *substituted judgment*. This seems consistent with respect for autonomy and applies to most adults and perhaps at least to some extent to many older adolescents. For patients who have never been competent, such as small children, autonomy or previously expressed wishes are not relevant. Here, the *patient's best interest standard* should be central to the decision. This holds that decisions should be made for a patient based on weighing the relative benefits and burdens to the patient of

the treatment under consideration.^{1,2} It is, then, a standard based largely on the principle of beneficence.

What would be in this child's best interests?

In this case, one could argue that it is in the patient's best interest to live as long as possible, regardless of prognosis, justifying the use of life-prolonging measures such as mechanical ventilation, medically administered nutrition and hydration, and extensive resuscitation. Such an argument could be based on religious beliefs, but the choice to value life over other considerations need not be made solely on religious grounds. By this reasoning, the benefit of being alive outweighs or trumps the burdens of the ongoing intensive care. Others could argue that quality of life may sometimes matter more. An artificially prolonged life with associated burdens of many interventions, yet without meaningful social interaction or the possibility of regaining any meaningful interaction, is not in the patient's best interest. Further, complying with the parents' requests to prolong life, via cardiopulmonary resuscitation (CPR), mechanical ventilation or medically administered nutrition and hydration, for example, could perhaps result in additional harm (burden) to the patient by causing unintentional pain and suffering. By this reasoning, the benefit of being kept alive is outweighed by the burden of possible pain, indignity, or other factors.

In this way, determining the child's best interest requires a consideration and comparison of all relevant burdens and benefits to the child of the treatment under consideration. Clearly, this will often be a very subjective judgment. Participants should be asked to consider and discuss which of these approaches they feel is preferable.

If best interest is often a subjective value judgment, whose values should count the most?

In general, the values of the family should be determinative. Parents should be given wide discretion, and are not always required to choose what is (in the opinion of the physicians) in the child's best interest. But, if they reach a decision that is *clearly opposed* to the child's interests, with major consequences, pediatricians should consider overriding their decision, with court assistance if necessary and if time allows.⁷ For this case, participants should discuss whether they feel the parents' decision meets that threshold, thus obligating the physicians to seek to override it.

What if parents refuse a treatment recommended by the physician?

The same threshold should be sought. Is their choice merely suboptimal, or is it *clearly opposed* to the child's best interests? It may become difficult to determine. A useful guideline for all pediatricians, however, has been provided by the AAP Committee on Bioethics: "All children are entitled to effective medical treatment that is likely to prevent serious harm, or suffering, or death."⁸ In the rare case in which a pediatrician is concerned that a child is being denied this basic right because of parental choice, help from others, such as the hospital ethics committee and (in rare circumstances) the court, should be sought as time allows.

Is it appropriate to consider the interests of others, such as the other family members, when making medical decisions for a child?

It is widely held that the benefits and burdens *to the patient*, and not the family, the medical team, or society, are the relevant considerations. This is what is meant by *patient's best interest*. It has also been suggested, however, that it is reasonable for parents to consider potential benefits and burdens to the entire family in making their decision, or for the medical team to consider the interests of society (eg, financial costs) in determining what choices are made available to the patient or family.⁹ Participants should discuss whether they prefer the stricter patient's best interest standard or a broader inclusion of the interests of other people affected by decisions.

What should be done in this case?

In a case such as this, the medical team might feel that ongoing intensive measures and CPR would be inappropriate. Would it be ethically permissible to withdraw life-sustaining medical treatment despite parental objection? Would it be permissible to continue treatment as they have requested? These questions should be discussed in the seminar, based on the previously described considerations, and including the following points. However, it is essential at the outset to emphasize the importance of patience and compassion when working with parents who have been so devastated, and how their state of mind could influence their ability to work through the decision-making process.

One could argue that complying with the parents' requests to attempt to prolong life via mechanical ventilation, medically administered nutrition and hydration, and CPR, for example, could harm the patient by causing additional pain and suffering. Further, doing so would be very unlikely to provide significant benefit to the child if there was an extremely poor prognosis. By this reasoning, it could be permissible to withdraw life-sustaining medical treatment and refuse extensive resuscitative measures despite parental request, while providing adequate comfort measures based on an assessment of the child's interests. Furthermore, some who feel the benefits and burdens to individuals in addition to the patient should be considered might feel that withholding or withdrawing these treatments would be more consistent with the interests of those from whom resources would be diverted by maintaining the status quo.

The counterargument would be that there may be a chance for survival, and the values of the family may be such that any survival is a worthwhile goal. If informed parents wish to continue life-sustaining treatment, realizing that their child may not regain her former quality of life or could be permanently neurologically devastated, and sufficient pain control is achieved, it would be *permissible* to continue life-sustaining medical treatment, thus respecting the parent's right to parental authority. Where there is a chance for long-term survival and pain is adequately controlled (which should most often be attainable), parental preference for ongoing treatment should be respected, even if the medical team feels it to be inadvisable.

The physician's decision will require consideration of the rights and obligations discussed up to this point, and weighing the 2 arguments just presented. Some believe, and it is here suggested, that certain rare cases might be so bleak (some prognoses so

poor) that it is inappropriate to offer CPR and is appropriate to otherwise limit life-sustaining treatments. This is particularly true when patients appear to be suffering. In such cases in which options might be limited over parental objection, physicians should seek input from others, such as a second opinion, hospital ethics committee, and legal counsel. Many hospitals also have policies that specifically address such situations. But just as great emphasis should be placed on the values and preferences of the family, great caution is advised whenever considering overriding those preferences. It should be an occurrence of last resort. There may be some cases in which a child's dying is being significantly prolonged, and her suffering thus continues, to benefit others (eg, parents), and this is generally not appropriate. However, one should also consider that parents faced with such devastating information may need some time to understand and accept the situation. During this time it is the responsibility of the clinical team to give the patient adequate pain control, and give the family the support they need.

Participants should discuss the relative merits of these arguments and whether the severity of the prognosis in this case justifies withholding treatment despite parental request.

Conclusions and Suggestions

Decision making involving the health of children should include the physician, parents, and when possible and developmentally appropriate, the children themselves. Effective communication between these groups is paramount. Although an understanding and application of the principles outlined herein will be essential to decision making, conflicts and potential conflicts are most often resolved or avoided by open, frequent communication among all those participating in the decision.

References

1. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 6th ed. Oxford, England: Oxford University Press; 2009:99, 114, 138, 207, 371
2. Cummings CL, Mercurio MR. Ethics for the pediatrician: autonomy, beneficence and rights. *Pediatr Review*. 2010;31(6):1-4
3. Forman EN, Ladd RE. Making decisions – whose choice? In: Ladd RE, ed. *Children's Rights Re-Visioned*. Belmont, CA: Wadsworth Publishing Co; 1996:175–183
4. *Prince v Massachusetts*, 321 US 158 (1944)
5. American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314-

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