

## **Session 6. Parent-Patient-Pediatrician Relationship: Obligations of Veracity, Fidelity, and Confidentiality**

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### **Overview**

Over the last few decades, there has been a shift in the medical decision-making approach from a paternalistic to a shared decision-making paradigm, one that recognizes all parties involved in the medical decision bring essential elements to the doctor-patient relationship. Shared decision making requires a willingness to trust by all parties. Parents need to trust the physicians to have skill and competence, children need to trust their parents to have their best interest at heart, and pediatricians need to trust that families know their children and have a true understanding of their capacities and limitations. This shift in the decision-making process to a shared paradigm must take into consideration the developmental trajectory of the child and the increasing participation of the child in the decision-making process.

The development of a trusting relationship between a pediatrician, parent, and child is at the center of the American Academy of Pediatrics concept of the medical home. Yet multiple barriers to the development of trusting therapeutic relationships exist. These include an increasingly mobile population, health insurance shifts, and situations in which a new relationship must be forged rapidly because of a medical crisis. In a therapeutic relationship, a pediatrician assumes the obligations of veracity, fidelity, and confidentiality. These obligations can be simply defined. Veracity is a devotion to the truth or truthfulness. Fidelity is understood as being faithful and trustworthy, and confidentiality is an implicit or explicit promise by the physician to not divulge a patient's personal information without his or her permission. By assuming these duties, physicians create a solid foundation for effective communication. Communicating with families is a skill that can be developed and will increase a physician's ability to address medical problems.

How does a physician balance the competing and sometimes conflicting goods of confidentiality, veracity, and fidelity? When is it acceptable for a physician to deny a parent authority over what information to give a child? How do you resolve conflicts between the parent's values and those of the medical profession? What weight should be given to family specific values and at what developmental stage to the child's specific values? What are the goals of medicine and are the goals of the child/parent/and physician the same?

## **Instructor's Guide**

- Case Summary
- Alternative Cases
- Learning Objectives
- Suggested Reading for Instructor
- Further Reading
- Case Discussion
- Conclusions and Suggestions

## **Case Summary**

A 12-year-old female is referred to you for primary care by an infectious disease specialist at the university medical school. She is HIV positive, she does not know her diagnosis, and the parents do not want you or any of the staff to discuss her diagnosis with her. She was adopted as an infant, and her HIV status was not known by the adoptive parents until sometime after the adoption. The patient knows her mother died when she was a toddler and that those life circumstances meant her biological mother was unable to care for her, although she wanted the best for her child. The patient was recently in the hospital with respiratory problems and although she improved, she is asking questions.

## **Alternative Cases**

1. A 15-year-old female, the daughter of family friends, is a patient you are following for obesity and hypertension. She was seen by a colleague on your day off and was found to be pregnant. She does not want her parents to know. Given her hypertension and the pregnancy, she is at some medical risk, but she promised to follow up on all her obstetric appointments and will tell her parents at some later time. You see her parents at least once a week in a social setting.
2. You are caring for a child with asthma and his mother brings him in because he is wheezing. The parents are divorced. He was with his father over the weekend and he now has a cough and cold and has some wheezing. Mom is convinced he is worse because dad is a smoker and was smoking around him. She accuses the father in front of the child and wants your help to get sole custody. Mom wants you to write to the court to inform them the father is medically negligent by continuing to smoke around their son and therefore putting the child at increased risk.
3. A 12-year-old new patient is brought in by his parents with a past history of several episodes of wheezing. The father looks uncomfortable while you are asking about any family members with asthma and asks to speak to you in private. In private, the father tells you that the child was conceived via donor insemination and states he does not want his son to know.

## Learning Objectives

1. Discuss the basic of the duty of medical confidentiality, veracity, and fidelity and its application to the patient and family.
2. Address a parent's right to influence the medical care of his child as well as the physician's responsibility to function as a moral agent.
3. Recognize situations in which these respective duties are potentially in conflict- for example, when a family wants information withheld from an older child or when a child and parents disagree on the course of action that should be taken.
4. Identify strategies for preventing or resolving these conflicts.

## Suggested Reading and Resources for Instructor

American Academy of Pediatrics, Committee on Bioethics. Pediatrician-family-patient relationships: managing the boundaries. *Pediatrics*. 2009;124(6):1685-1688. Reaffirmed January 2014

American Academy of Pediatrics, Committee on Bioethics. Communicating with children and families: from every day interactions to skill in conveying distressing information. *Pediatrics*. 2008;121(5):e1441-e1458

American Academy of Pediatrics, Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics*. 2016;138(2):1-7

Lantos JD. Should we always tell children the truth? *Perspect Biol Med*. 1996;40(1):78-92

Lantos JD. The patient-parent-pediatrician relationship: everyday ethics in the office. *Pediatr Rev*. 2015;36(1):22-29

Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics*. 2014;133(Suppl 1):S24-S30

Sigman GS, Kraut J, La Puma J. Disclosure of a diagnosis to children and adolescents when parents object: a clinical ethics analysis. *Am J Dis Child*. 1993;147(7):764-768

Ross L. *Children, Families, and Health Care Decision Making*. New York, NY: Oxford University Press; 2002

## Further Reading

Trueman Katz Center for Pediatric Bioethics. 2015 Annual Conference: The Delicate Triangle: Responsibilities and Challenges in the Provider-Patient-Parent Relationship. Available at:

<http://www.seattlechildrens.org/research/initiatives/bioethics/events/pediatric-bioethics-conference/2015-pediatric-bioethics-conference/>.

Answering parents' questions. *J Clin Ethics* (special section) 2003;14:59-87

## Case Discussion

### *Analysis of the duties*

In this case, the duties to the parent for confidentiality are in potential conflict with the duty to tell the patient the truth. This highlights a challenge in pediatrics when the pediatrician has a legal obligation to the parents (or legal guardian) and a moral obligation to the patient. A failure to answer a patient's direct questions and failure to respect a parent's understanding of what is in the best interest of their child both have the potential to put the therapeutic relationship at risk.

### *Is truth telling a moral imperative or is it a virtue?*

One physician's personal moral values may cause him to view an element of deception as therapeutic and justified in this setting. For another physician, any deception is wrong, no matter what the consequences. The social, legal, and economic climate can influence a physician's personal values. The importance of individual autonomy as a highly valued good, especially in Western society, combined with the legal role of informed consent, has altered physician practices in favor of recognition of the patient's right of self-determination and full disclosure. The move toward a pediatric patient's right of self-determination becomes more prominent as adolescence approaches. Most states have legislation to protect adolescent's independent decision making in areas like reproductive health.

### *What is the justification for lying to the patient or willfully hiding the truth?*

In this case, the parents feel that the emotional and cognitive burden of knowing she is HIV positive will damage their daughter's memory of her mother and affect meaningful relationships with peers. The stigma associated with HIV is so significant, and the prevailing popular belief in the United States is that it is associated with high-risk sexual behavior (homosexual lifestyle and prostitution); the adoptive parents believe that she will suffer from the association, although incorrect in her case. Middle school students as a group are known for their propensity to form cliques and exclude those who are different.

Her parents have told her she has a blood disease, and she is compliant with treatment. Her biological mother died from the disease and although the daughter knows she is adopted and her mother is dead, the adoptive parents do not wish to discuss that the child

has the same disease as her mom or that it is fatal. In addition, they wish to avoid a discussion of transmission. The adoptive parents have tried to portray the biological mother as a caring woman who wanted what was best for the child, especially after she knew she was sick. Because HIV is likely to be discussed at school in health class and information is available on the Internet, all of these facts would likely come to light if her disease were to be formally named.

***Should physicians always tell the truth, the whole truth and nothing but the truth?***

Physicians often inform patients of some, but not all, risks of a procedure or medication. In doing so, they make judgments about what information is essential for the patient to know and what ultimately they tell the patient. In this sense, withholding some information is common in the practice of medicine. Historically, physicians were regarded as ministers of hope and comfort to the sick. When diagnostic options were extremely limited and treatment options relatively nontoxic, doctors often believed that comforting and caring for the sick and suffering was more important than full disclosure and were known to withhold specific stressful information. In certain cultural contexts and frequently with children, withholding stressful information or controlling the way a severe medical illness is presented to a child is considered to be for the patient's good. In modern day medical practice, physicians may have information about the long-term health consequences of a screening test (or genetic test) on a patient who is asymptomatic and does not know they have a disease. In addition, treatment options have expanded exponentially and different treatments may have different risk-benefit ratios. Experimental treatments may be available with varying toxicities. Given these significant changes in the options available to patients and the litigious environment in which modern medicine is practiced, fully informed consent has become both the legal and moral obligation of the physician.

**Patient Factors**

***Is the duty to respect a patient by allowing her to make decisions altered by the patient's inability to make a decision?***

Although children are unable to make medical decisions at younger ages, the fact is that children mature, become more independent and able to make choices. The AAP has promoted the concept of pediatric assent in recognition of this developmental trajectory. Both pediatricians and parents have fiduciary responsibilities during this developmental trajectory to protect and promote the child's health-related interests. Patients have both cognitive needs to know and understand what is happening to them and affective or emotional needs to feel known and understood. A parent's request to shield a patient from specific knowledge is less morally objectionable at younger ages. As maturation progresses and a child's ability to understand information increases, there is an increasing moral obligation to the pediatric patient to honor his specific requests. This has the potential to place a parent's concept of what is best for the child in conflict with a physician's view of what is in the best interest of the child. These conflicts challenge parents' rights in a liberal society to raise their child according to their own values.

In this case, the child is fully participating in her care but does not know the specifics of her illness. She feels cared for and understood by her parents, who have answered her

questions about her illness in a vague way. There is no conflict about the medical care of the child; however, there is a conflict about what the child should be told about her disease.

### **Family Factors**

*What does it mean to respect the family's values? What harm may come to the child as a result of disrupting a stable system of social support provided by the family? What harm to the therapeutic relationship may result if a physician imposes his values on these parents?*

Respecting a family's values means recognizing that parents have the primary role in helping to define what constitutes their child's well-being and their understanding of the good. It means a physician needs to respect parents' interest and the freedom to raise their child according to their own values. The parents are responsible for providing a child's basic needs, and that includes opportunities to assist in the development of the child as a moral person. The needs of all members of a family may influence a health care decision that addresses a single child. A physician who superimposes his or her own values over a family's has the potential to do harm by destroying a doctor-parent-patient relationship and upsetting a stable support system for the child.

### **Disease-Specific Factors**

*Does knowing about the disease positively affect its course and prognosis?*

Stronger arguments for full disclosure of disease status can be made for diseases in which a child's knowledge of the disease will positively affect its course. Diabetes is an example for which self-care would be impossible if a child were unaware of the diagnosis. In the case under discussion, the child knows she is sick and is fully compliant without knowing her diagnosis. This makes the parents' argument for less-than-full disclosure stronger. The child is adopted; the adoptive parents have no personal risk from revealing the HIV status of the child. However, this does not lessen their concern about the psychological effect of full disclosure.

*Does knowing the diagnosis and prognosis affect the adjustment process or prognosis?*

*Does knowing the facts of the disease help the patient to plan her life?*

Often, a good case can be made for full disclosure of a diagnosis, because a variety of support groups exist for many conditions and interaction with other families, and children with similar illnesses can be therapeutic. It is also possible that nondisclosure may give the child the idea that the diagnosis is a "secret," and keeping the secret, in some cases, may be a burden to the child. Children often wish to protect their parents from pain just as parents wish to protect their children. In this case, there are no disease-specific support groups available for this family, and the prognosis for her does not influence or change the family's goal of doing their best to live a "normal" life with a chronic, life-threatening condition

## Conclusions and Suggestions

Respect of patients and their families is a cornerstone of the doctor-patient relationship, and respect should be maintained even in situations in which physicians may disagree with a family's decision. Parents deserve wide latitude in determining what the best is for their child. In conversations in which there is a difference of opinion between the parents and physician, it may be helpful to articulate deeply held beliefs about what having a good life means. Often, the differences are rooted in different sets of values about the nature and meaning of life. When the respective worldviews are shared, both parties will often feel heard and understood, even if they cannot come into agreement. In the case presented, there was sufficient agreement between the family's values and the pediatrician's. In cases in which agreement cannot be found, physicians have the choice to refer patients for care to another physician, with the family's consent.

*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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