Session 9. Pediatrician-Parent-Patient 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 that all parties involved in the medical decision bring essential elements to the therapeutic relationship. Shared decision-making requires a willingness to trust by all parties. Parents need to trust physicians to have skill and competence; children need to trust their parents to have their best interests 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 also overlays a developmental trajectory in which the wishes of the child are increasingly relevant.

The development of a trusting relationship between a pediatrician, parent, and child is at the center of the American Academy of Pediatrics (AAP) conceptualization 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 settings where 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. 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.

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Case Summary
A 12-year-old female is referred to you for primary care by an infectious disease specialist at the university medical school. The patient is HIV positive; she does not know her diagnosis, and her 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, though she wanted the best for her child. The patient was recently in the hospital with respiratory problems and though she improved, she is asking specific questions about her health status.

- How does a physician balance the competing and sometimes conflicting goals of confidentiality, veracity, and fidelity?
- How do you resolve conflicts between the parents’ values and those of the medical profession?
- When is it acceptable for a physician to deny a parent authority over what information to give a child?
- What are the goals of medicine, and are the goals of the child, parent, and physician the same?

Alternate Cases
1. A 15-year-old female is the daughter of family friends and 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, cold, and some wheezing. The mother is convinced he is worse because the father, a smoker, 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 inform the court that 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. There, the father tells you that the child was born via donor insemination and states that he does not want his son to know.

Learning Objectives
1. Discuss the basis of the duty of medical confidentiality, veracity, and fidelity and its application to the patient and family.
2. Address a parent’s right to direct care 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 (eg, when a family wants information withheld from an older child, when a child and parent disagree on the course of action that should be taken).
4. Identify strategies for preventing or resolving these conflicts.

Suggested Reading for Instructor
http://aappolicy.aappublications.org/cgi/content/full/pediatrics;124/6/1685. Accessed May 12, 2011

http://aappolicy.aappublications.org/cgi/content/full/pediatrics;103/1/164. Accessed May 12, 2011

http://aappolicy.aappublications.org/cgi/content/full/pediatrics;121/5/e1441. Accessed May 12, 2011

**Further Reading**


(This special section of *The Journal of Clinical Ethics* contains commentaries by leading ethicists that explore the many facets of this question. This is a must read for all clinicians, generalists, and subspecialists.)


Case Discussion
Analysis of the Duties
In this case, the duty of confidentiality to the parent is in potential conflict with the duty to tell the patient the truth. This highlights a challenge in pediatrics in which 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 to respect a parent’s understanding of what is in the best interest of the child have the potential to put the therapeutic relationship at risk.

Is truth telling a moral imperative or a virtue?
One physician’s personal moral values may view an element of deception as therapeutic and justifiable 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 more in favor of recognition of patient rights of self-determination and truthful disclosure. The move toward a pediatric patient’s right of self-determination is especially prominent as adolescence approaches, and most states have legislation to protect adolescents’ 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 further distance her from meaningful relationships with peers. The stigma associated with HIV is so significant and the prevailing paradigm in the United States is that of high-risk sexual behavior (eg, homosexual, prostitution). The adoptive parents believe she will suffer from the association—even though it is incorrect—that she is a prostitute or gay. Middle school students as a group are known for their ability 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 while the daughter knows she is adopted and her mother is dead, the 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 parents have tried to portray the biological mother as a caring woman who wanted what was best for her child, especially after the mother 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 salient and what they convey to the patient. In this sense, withholding some information is common in the practice of medicine. Historically, physicians were felt to be ministers of hope and comfort to the sick. When diagnostic options
were extremely limited and treatment options relatively nontoxic, doctors often felt 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 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 patients who are not having any symptoms and do 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 an element of the legal and moral obligations of the physician.

Patient Factors
*Is the duty to respect a patient by allowing that patient to make decisions altered by the patient’s inability to make a decision?*

While children are unable to make decisions at younger ages, the fact is that children outgrow their dependent states. The AAP has promoted the concept of pediatric assent in recognition of this developmental trajectory. Pediatricians and parents have fiduciary responsibilities during this developmental trajectory to protect and promote the child’s health-related interests. Patients have 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 young ages. As maturation progresses and a child’s ability to understand information increases, there is an increasing moral obligation to the patient to honor 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 best. These conflicts challenge a family’s right in a liberal society to raise a child with its 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 family, who has 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 or her values on 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 a parent’s interest and freedom to raise a child with the parent’s own values. Parents are responsible for providing all a child’s basic needs and that includes opportunities to assist in the development of the child’s moral person. The needs of all members of a family may influence a health care decision related primarily to one child. A physician who superimposes his or her own values over a family’s has the potential to do harm by destroying a therapeutic relationship and upsetting a stable support structure 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 in which self-care would be impossible if a child did not know about the disease. In the case under discussion, the child knows she is sick and is fully compliant without knowing her diagnosis. This makes the parent argument for less than full disclosure stronger. The fact that she is adopted and knows it is important because in the case of HIV, her adoptive parents are not in the chain of HIV transmission and are not a risk of having their HIV status disclosed. 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 with children because a variety of support groups exist for many conditions and discussions with other families and children with similar illnesses can be therapeutic. It is also possible that children perceive that there is a secret, and keeping the secret in some cases may be a burden to them. 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 the patient does not influence or change the family’s objective of doing its best to live a “normal” life with a chronic, life-threatening condition.

Conclusions and Suggestions
Respect for patients and their families is a cornerstone of the therapeutic relationship, and respect should be maintained even in settings where physicians may disagree with a family’s decision. Parents deserve wide latitude in determining what is best 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 assumptions about what having a good life means. Often the differences are rooted in different sets of presuppositions about the nature and meaning of life. When the respective goods are ordered and shared, those participating in discussion often feel heard and understood even if they cannot come to agreement. In the case presented, there is sufficient agreement about the ordering of the goods, and care of the patient was accepted by the primary care physician. In cases in which agreement cannot be found, physicians have the opportunity to refer patients for care to another physician of the family’s choice.

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