Session 7. Ethical Issues in the Care of Adolescents

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Overview

Caring for adolescent patients can be one of the most rewarding experiences in pediatrics. A competent and confident approach to the adolescent patient must include an understanding of the ethics issues that arise in everyday adolescent medicine. Physicians must balance respect for the patient's developing capacity for decision making with the ongoing need for support and guidance from caring adults. Concerns about confidentiality, management of high-risk behavior, parent/adolescent conflict, and emerging independence are part of the adolescent experience.

This module will work to enhance understanding of the stages of adolescent development and the ethical concerns most salient to each, the ethical and public health approach to limited confidential care for adolescents, and the importance of and limits to parental control over adolescent health care choices. Focus will be on preventive ethics; establishing an approach to adolescent patients that can avoid some of the most frustrating and predictable ethical dilemmas. It will seek to encourage providers to embrace the particular experience of adolescent care with confidence.

Instructor's Guide

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

Case Summary

Michael is 17-years-old and has been your patient for 7 years. He is generally well and has been a good student and now is a leader on the school soccer team. You are aware that there has been some discord in the family lately, after Michael got a tattoo against his parents' wishes. Michael is in clinic today for a routine well examination and sports preparticipation physical. He is accompanied by his father, who waits outside while you complete your interview and physical examination. During your examination, Michael says that he does not want you to give his father any information about his health status. Your evaluation reveals moderate blood pressure

elevation and a new genital rash, most consistent with tinea cruris. Michael does reveal that he has initiated sexual activity with his girlfriend, and that they use condoms infrequently. He denies alcohol, tobacco, or drug use. He comments that his parents are overbearing and difficult and that he wants to take more control of his own life. When you leave the room to allow Michael to dress, his father asks you: "How is he – anything I should know?"

1. How should you handle Michael's request for confidentiality?
2. What if he were 13 instead of 16?
3. What is the basis on which we offer confidential care for adolescents?
4. How can physicians caring for adolescents avoid conflicts around confidentiality?

Alternative Cases

1. Shari, 14-years-old, and her mother, Ms Evers, come to the acute care clinic. Shari is healthy, moderately cognitively delayed, and emotionally very young. Chief complaint, per the registration documents, is headaches and cough. As you are entering the examination room, Ms Evers asks to speak with you outside. She explains that Shari is well, no headaches or cough, but that she needs birth control initiated immediately. Ms Evers notices that Shari looks older than her age and she is worried about the neighborhood boys who are "hanging around". Ms Evers would like you to start an injectable contraceptive. Shari's behavior has not changed, but Ms Evers became pregnant herself at age 16 and is concerned that Shari will be victimized and become pregnant. Ms Evers is a single mother and cannot afford to raise a grandchild. You speak with Shari alone – she denies any interest in sexual activity and seems embarrassed by the conversation. Based on your conversation, you see that she actually has minimal understanding of reproduction.
    - Is it acceptable for this mother to request contraception despite her daughter's general lack of interest in sexual activity?
    - How should the provider manage this interaction?

2. Allen is 15-years-old. He has had some difficulty with school avoidance, but never trouble with the law or, to your knowledge, with drugs or alcohol. His parents accompany him to the clinic visit today. During your initial interview, the parents angrily accuse Allen of staying out all night long and using drugs. Allen is quiet and does not respond to his parents. He makes eye contact with you, surreptitiously rolling his eyes. Allen's parents demand that you test his urine for drugs and alcohol. They threaten to throw him out of the house if the test results are positive.
    - How can the provider manage this situation?

Learning Objectives

1. Develop sensitivity to the stages of adolescence and the ethics issues most common within each age.
2. Understand the reasons adolescents are offered confidential care and the limits to the duty to protect confidentiality.
3. Identify limits to parental authority over the care provided to adolescent patients.
4. Develop strategies to avoid the ethical issues most common in everyday clinical care of adolescents.

Suggested Reading for the Instructor

Ford E, English A, Sigman G. Confidential healthcare for adolescents: position paper of the Society of Adolescent Medicine. *J Adolescent Health*. 2004;35(2):160-167

Gilbert A, et al. Clinical conversations about health: the impact of confidentiality in preventive adolescent care. *J Adolesc Health*. 2014;55(5):672-677

Jones RK, Purcell A, Singh S, Finer LB. Adolescents' reports of parental knowledge of adolescents' use of sexual health services and their reactions to mandated parental notification for prescription contraception. *JAMA*. 2005;293(3):340–348

Guttmacher Institute. An Overview of Minor Consent Laws. Available at: https://www.guttmacher.org/state-policy/explore/overview-minors-consent-law. Accessed March 7, 2017

Case Discussion

Confidentiality in the care of adolescent patients has both intrinsic and instrumental value. One of the central principles of biomedical ethics is the duty to respect autonomy. Clinicians caring for pediatric and adolescent patients are quick to surmise that the duty to respect autonomy is complicated by the fact that autonomy is a developmental construct. As children develop cognitive and emotional capacities, our autonomy-related duty moves from protecting and promoting the developing autonomy of young children, toward respecting the decisions made by adolescents who have decision-making capacity similar to that of adults. As an intrinsic value in medicine, protection of confidentiality is a commitment to respect autonomy and the dignity of patients.

As an instrumental value, the promise of confidential care increases the likelihood that adolescent patients will seek care and offer frank disclosures of health concerns. Both values are especially important in the care of adolescents, who, from a developmental perspective, are seeking to achieve autonomy from their parents and are learning to make appropriate decisions about a variety of issues, including healthy behaviors and seeking health care.

The challenge in adolescent health care is to balance these intrinsic and instrumental values of confidentiality with the duties to promote adolescents' well-being and avoid harms. Although adolescents are developmentally programmed to seek independence, families remain, in most situations, their primary source of moral and financial support and protection. The clinician should seek to enrich family connections while encouraging healthy independence.

Clinicians caring for adolescent patients will be more successful in analyzing and managing ethical concerns if they interpret adolescent behavior in terms of the stages of adolescence. Generally, early adolescence includes ages 10-13, middle adolescence ages 14-16, and late adolescence ages 17-21.

The table below diagrams the changes in physical, moral and cognitive dimensions as adolescent development progresses.

	Early Adolescence	**Middle Adolescence**	**Late Adolescence**
Age	10-13	14-16	17-20 and beyond
Somatic	• Secondary sex characteristics • Beginning of rapid growth • Awkward appearance	• Height growth peaks • Body shape and composition change • Acne and odor • Menarche/spermarche	• Physically mature • Slower growth
Cognitive and moral	• Concrete operations • Unable to perceive long-term outcomes of current decision making • Conventional morality	• Emergence of abstract thought (formal operations) • May perceive future implications, but may not apply in decision-making • Questioning mores	• Future-oriented with sense of perspective • Idealism; absolutism • Able to think things through independently
Self-concept/identity formation	• Preoccupied with changing body • Self-consciousness about appearance and attractiveness • Fantasy and present-oriented	• Concern with attractiveness • Increasing introspection • "Stereotypical adolescent"	• More stable body image • Attractiveness may still be of concern • Firmer identity

Family	• Increasing need for privacy • Increased bid for independence	• Conflicts over control and independence • Struggle for acceptance of greater autonomy	• Emotional and physical separation from family • Increased autonomy
Peers	• Seeks same-sex peer affiliation to counter instability	• Intense peer group involvement • Preoccupation with peer culture • Peers provide behavioral example	• Peer group and values recede in importance • Intimacy/possible commitment takes precedence
Sexual	• Increased interest in sexual anatomy • Anxieties and questions about genital changes, size • Limited dating and intimacy	• Testing ability to attract partner • Initiation of relationships and sexual activity • Questions of sexual orientation	• Consolidation of sexual identity • Focus on intimacy and formation of stable relationships • Planning for future and commitment

Adapted from Holland-Hall C and Burstein G. "Adolescent Development". Kliegman RM, Stanton BF, St Geme JW, Schor NF , eds. *Nelson Textbook of Pediatrics.* 20th ed. Philadelphia, PA: Saunders Elsevier; 2016. p. 927

As clinicians analyze ethical concerns arising in the care of adolescents, the particular stage of development of the specific patient is an important piece of the puzzle. Parents locked in combat with a child whose behavior seems extraordinary may be comforted if the behavior is presented in terms of normal development.

Case 1: Discussion

Michael is entering the later stage of adolescence, marked by increased autonomy and emotional separation from his family. At this stage, he may have significant capacity for medical decision making but is still financially, legally, and emotionally under the care of his parents.

Laws vary from state to state, but most states offer adolescents confidential care for reproductive health issues, such as treatment of sexually transmitted illnesses and contraception. (See the Guttmacher Institute for up-to-date state laws.) Access to confidential care is not based on an intrinsic value of respect for adolescent decision making, but an instrumental value in promoting the public's health by removing barriers to reproductive health and sexually transmitted disease treatment for adolescents.

Michael's visit is not a reproductive health care visit, but a general examination. His request to withhold all information from his father will not have statutory support. It can, however, be interpreted as a positive desire to take charge of his own health, consistent with his developmental stage. If he were an early adolescent, the same behavior might be interpreted as a

fairly hollow bid for independence, more an expression of fantasy than an expression of adult capacity for decision making.

This case highlights the importance of preventive ethics – making sure that all parties know what to expect in terms of confidential care prior to the visit and any sensitive disclosures. Michael should know the limits of his right to confidential care. His father should be informed also. This is an excellent opportunity to honor Michael's desire to take charge while striving to strengthen his connection to his father's desire to help Michael thrive. Michael's history of sexual activity, the provider's counseling about condom use and *tinea cruris* can be kept confidential. Michael can be encouraged to report his blood pressure issue and his general good health to his father himself at the end of the visit. Michael and his father should be encouraged to come to shared understanding about general health visits and information sharing.

Conclusions and Suggestions: Case 1

1. Requests for confidential care and increasing participation in health care decisions can be supported as normal development in adolescents. Anticipatory guidance to families and adolescents should include the parameters for confidentiality.
2. Statutory support for access to confidential care for reproductive health is based in a public health concern for limiting transmission of sexually transmitted disease and unwanted pregnancy, not a belief that adolescents should be making independent decisions about sexual and reproductive health.
3. It is important to interpret requests for control over health care decisions and information in light of an individual adolescent's stage of cognitive and emotional development.

Case 2: Discussion

This case challenges us to interpret parental decision making and consider the nuances of parental authority over an adolescent. If Shari, at the age of 14, were cognitively normal, there would be a strong argument to involve her in any decisions about reproductive health and a very strong argument to refuse to initiate injectable contraception without her knowledge and consent. In this case, however, the focus is on the child's best interests and balancing risks and benefits of contraception in a child whose physical development has outpaced her delayed cognitive development.

Parents are charged with protecting their children's interests and are generally offered fairly wide leeway in making health care decisions for children. Parents are usually best placed to make choices for children because they are emotionally invested in their children and have the most intimate knowledge of their children's lives. Challenges to parental authority are most commonly based on concerns for the best interest of the child. In adolescent care, challenges to parental authority can also be based on a duty to respect the developing autonomy of the adolescent.

In this case, Shari is at risk because her physical development and her cognitive development are not synchronized. Because of her cognitive impairment, they may never be. Her mother's concern for Shari's wellbeing seems realistic. At the same time, it is not clear whether Shari's

mother is responding to an actual threat or to her own traumatic childhood. Management of this case requires an assessment of the potential benefits and risks of injectable contraception for this particular child. Benefits and risks to the family matter as well; the risk of an unwanted pregnancy in a child who is not capable of caring for offspring must be considered. Additionally, a discussion of other means to protect this child from unwanted sexual contact, and a richer understanding of the mother's concerns and anxieties is necessary. The primary care provider's input should be sought; he or she may have a better understanding of Shari's actual cognitive capacity related to reproductive health. Finally, no matter what decision is made, appropriate care includes working to educate Shari about sexual behavior and self-protection, including appropriate contraception.

Conclusions and Suggestions: **Case 2**

1. Parents are, presumptively, the best decision makers for adolescents who do not have capacity to make decisions. The limits of parental authority are set by concerns for the best interests (or at least "good enough" interests) of the child.
2. Even if an adolescent patient cannot participate as a decision maker, efforts must be made to educate her and allow her to assent to care.

Case 3: Discussion

This case puts us in the middle of an angry confrontation between parents and an adolescent child. The challenge is to manage the confrontation appropriately while maintaining a therapeutic alliance with both patient and parents. The demand for drug testing, either surreptitious or not, is fairly common in adolescent care. Parents have legitimate and evidence-based reasons to fear early involvement with drugs and alcohol. Even in the absence of actual substance use, adolescent behavior is often inscrutable to parents, and drug use may arise as the best explanation for inexplicable changes in behavior.

Management of conflict between parents and an adolescent patient requires careful diplomacy and negotiation. Respect for parents, who are challenged to protect adolescent children during their exploration and risk taking phases of development, is paramount. At the same time, respect for the adolescent patient must be demonstrated. Failure on either count risks the therapeutic alliance and minimizes the likelihood of a successful encounter.

Conclusions and Suggestions: Case 3

After a careful presentation of some parameters for discussion, parents and adolescent can be interviewed together and then separately. The confidential nature of the adolescent interview should be presented to both patient and parents, with a clear statement as to the limits of confidentiality. Parents generally accept the need for confidential interviews, but if resistance emerges, a direct explanation of the importance of the routine confidential interview for purposes of safety and appropriate medical care is usually effective. Ongoing parental resistance to a confidential interview should be concerning.

Although the specific treatment plans will depend on the information obtained in the interviews, the goal for both is to establish a calm and organized plan for communication and strategies for management of challenging behavior. Family counseling options should be included. Spot urine drug testing is usually of limited value. It is often best to redirect the demand for immediate testing in favor of a more sustained approach to evaluation and management of substance use concerns.

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.