

An Exploration of the Ethical, Legal and Developmental Issues in the Care of an Adolescent Patient

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Abstract

Providers of health care to adolescent patients face numerous challenges. In addition to increased risk for many health problems, adolescent patients may bring complex ethical, legal and developmental questions to bear as they seek medical services. This article describes the case of one such adolescent patient and discusses some of the attendant issues faced by her physician. For example, providing reproductive health care to teenage patients without the knowledge of parents or guardians requires familiarity on the part of providers with relevant state and federal law. Additionally, providers must be aware of financial barriers and they need to acquaint themselves with available services such as New York State's Family Planning Benefit Program. Attention to their patients' stages of cognitive and emotional development should inform providers' advice to adolescents, and an understanding of the importance that supportive adult relationships play during adolescence is essential to fostering healthy development. Open communication between adolescent patients and their parents or guardians should be encouraged, while maintaining the primary obligation of providing confidential care.

Key Words: Adolescent health, confidentiality, health insurance, cognitive development, ethics.

CARE OF THE ADOLESCENT PATIENT involves various challenges for the clinician. In addition to knowing the common physical complaints and problems of teenagers, an understanding of the cognitive, emotional and psychosocial development that occurs during adolescence is essential for successful treatment and management of teenage patients. The adolescent patient poses not only a unique set of diagnostic possibilities to the clinician, but also distinct ethical and legal considerations. This article details a recent case involving an adolescent and explores some of the ethical and legal issues faced by the patient's physician. Though each adolescent patient brings his or her own unique challenges to those who provide medical care, this article addresses some of the difficulties providers may experience on a regular basis when caring for this population. An understanding of the extent and

limitations of confidentiality is of particular importance for patients, their families and medical providers. Moreover, it is imperative that providers strive to gain the trust of their adolescent patients, and to facilitate communication between patients and their parents or guardians.

Case

Jessica is a 15-year-old girl who has been a patient of the same pediatrician in New York City since the age of five. She comes in with her mother for a routine check-up. After asking her mother to step out of the room, the physician asks Jessica about sexual activity. Jessica confides that she is having consensual sex with her 17-year-old boyfriend. She has been using condoms intermittently, and has read about the contraceptive patch on the Internet. Jessica tells the doctor that her mother does not know that she is having sex, and would "kill her" if she found out. Jessica wants to have a prescription for the patch, but doesn't know how she will be able to afford it. Although she has private insurance through her family, she is worried that her parents will find out about the prescription if she uses the insurance to cover the cost. As her physician discusses the options available to her, Jessica also expresses concern about possible

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exposure to HIV and asks to be tested. However, she is concerned that the results would need to be shared with her mother if the test were to show that she is infected with HIV.

The Issue of Confidentiality

There are several issues that present themselves in Jessica's case. The primary concern for Jessica is that her mother not discover that she is sexually active. Disclosure of her history of sexual activity would have a significantly negative outcome, and thus Jessica is unwilling to share this information with her mother. However, she is a minor and seeks a prescription. Who has the right to consent for care in this case?

In general, parents or guardians have the right to give informed consent for the medical care of their minor children. However, there are circumstances in which exceptions to this rule apply.

The first exception applies to emancipated minors. "Emancipation" has been defined as the renunciation of parental right to a child (1–3). A minor is considered emancipated if one of the following events has occurred: he or she is married; he or she is in the armed services; he or she has established a home and is financially independent; or his or her parent has failed to fulfill parental support obligations and the minor seeks emancipation. In general, emancipated minors can consent to their own health care (4). According to the New York Civil Liberties Union, the few New York courts that have addressed this issue have all consistently decided in favor of allowing emancipated minors to give consent (1).

The second exception is based on the mature minor doctrine, which has been established by legal precedent in many states. A minor may consent to medical care and treatment without parental consent if the physician determines that the minor has the maturity to make independent decisions. In New York, a mature minor is a minor who is emotionally and intellectually mature enough to give informed consent and who lives under the supervision of his parent or guardian (1). The mature minor doctrine usually applies whenever no other exceptions to parental consent apply, and parental involvement is impractical or problematic, or may discourage the adolescent from seeking needed medical care (5).

The third exception is based on the category of care the minor is seeking. In the State of New York, a minor who understands the risks and benefits of proposed and alternative treatments may generally make health care decisions without parental consent for reproductive health care, including family

planning, abortion, pregnancy-related care including prenatal care, care during labor and delivery, and care for sexually transmitted infections (STIs) (4). Confidential "comprehensive voluntary family planning services" are available via federal Title X funding to "all persons desiring such services," including "a special emphasis on preventing unwanted pregnancies among sexually active adolescents," with no stipulated age requirement (6). In addition, minors who can give informed consent can obtain confidential services regarding STI screening and treatment, and New York State law forbids the release of medical information to parents without the patient's permission (7). Thus, Jessica has the right to consent to confidential reproductive health services.

Because Jessica has expressed interest in HIV testing, she should be given the option of having either an anonymous test at a Department of Health site or a confidential test at her physician's office. In an anonymous test the patient's name is not revealed; informed consent and test results are tracked with a coded system that has no linkage to the patient's identity. Should Jessica decide to get confidential testing during her office visit, she must understand that her test results can be subject to reporting and contact notification. In particular, her physician must inform Jessica that if her HIV test result were positive, her name would be released to the Department of Health, as would the names of her known sexual contacts (8, 9). However, she would not be required to give contact information for her sexual contacts (such as her boyfriend), and she would not be denied treatment or be criminally prosecuted based on failure to disclose (10). In addition, even though Jessica can consent to her own HIV testing, she must also be made aware that her results could be shared with her mother if her physician deems that she lacks sufficient maturity to consent for the necessary follow-up care (11, 12). She should also be reassured that such disclosure would only occur if the physician considered it medically necessary, and Jessica would be allowed a sufficient amount of time to disclose on her own.

Payment for Confidential Services

As a resident of New York State, Jessica has the right to consent to reproductive health care without parental notification. However, this case illustrates another difficult issue that may arise when caring for adolescent patients. The financial burden entailed in obtaining truly confidential health care is of paramount concern, as many adolescent patients lack funds to pay for care indepen-

dent of their parents or guardians. Unfortunately, involuntary disclosure can occur through billing or insurance records. This possibility of disclosure, whether actual or perceived, is one of the major barriers to accessing care among teenagers (13). Adolescents often express fear that any insurance or billing correspondence will prompt questions from parents or guardians. Most insurance companies require that the physician disclose the treatment offered as a stipulation for payment. This information is listed in the "explanation of benefits" statement (or EOB) that is mailed to the patient's home and often read by the patient's parents, even when addressed to the patient (14). Because parental disapproval of their children's sexual activity can, in some cases, manifest as verbal or even physical abuse, or in forcing the child to find another place to live, the negative impact of such breaches of confidentiality on patients' quality of life can be considerable.

This discrepancy between an adolescent's right to confidential care and the reality of lack of access because of insurance coverage has led New York to create a public health insurance program to help guard minors' confidentiality: the Family Planning Benefit Program (FPBP). Through FPBP, adolescents may apply for limited Medicaid coverage for family planning services without parental involvement in the application process. Teenagers are considered for eligibility without regard to parental income or insurance status, and family planning services will be billed to FPBP rather than to the patient's private insurance. EOBs are not sent to the patient, so that adolescents can receive services and providers can seek payment without worrying about breaches in confidentiality.

In New York State, FPBP offers a mechanism by which a significant barrier to confidential care can be overcome. Similar programs are available to adolescents in California (15). However, payment for confidential care may be a barrier to adolescents in other states. Federal funding for nationwide family planning services is available in the form of Title X grants; however, these funds may not be used for patients seeking abortion. Also, the ability of adolescents to obtain confidential care has been threatened by proposed legislation that would require parental consent for minors seeking treatment at a Title X-funded facility, but thus far such measures have been unsuccessful (16). An awareness of available resources is of particular importance to providers of care to adolescents, as this awareness may be the only means by which their patients can access appropriate confidential care.

Cognitive Development

By law, Jessica has the right to provide consent for her own reproductive health care and be enrolled in insurance programs to cover the cost of the treatment she chooses. From a legal perspective, she need never inform her mother of her decision at all. However, there are other issues for her health care provider to weigh when giving her not only medical care, but advice.

Adolescence is a time of rapid and often disorienting change for young people. Piaget has described the process of cognitive development at this age as a "liberation from the concrete in favor of interest oriented toward the non-present and the future" (17). Thus, the ability to connect their behaviors with current or future adverse outcomes is still developing in teenagers. However, preventable behavior is responsible for over half of adolescent morbidity and mortality (18). This reality is often well understood by parents or guardians, and the conflict between the patients' preferences and the teenager's own wishes may be significant. It is often left to the health care provider to mediate in these situations and find a mutually acceptable compromise.

During the transition from childhood to adolescence, a teenager's primary influences shift. Parents are often eclipsed by peers during early adolescence, and as development continues the patient eventually begins to make decisions based upon his or her own best judgment. This is an integral step in the achievement of "identity," which is the goal of late adolescence, according to Erikson (19). Young adults who perceive themselves to be primarily responsible for their own health, or have an internalized "health locus of control," are more likely to engage in healthy behaviors (20), and it is important to foster this emerging sense of autonomy. However, it is equally important for the physician to understand that Jessica may require more external guidance at this point in her psychosocial development.

Whenever possible, adolescents should be encouraged to communicate with their parents or guardians. Jessica's relationship with her mother should be fully explored by her physician. It is likely that Jessica anticipates a far worse reaction from her mother than would actually occur. Further, the physician should offer to facilitate the conversation between the two of them in the neutral setting of the health care environment. Should Jessica adamantly refuse to involve her mother in her family planning decisions, she and her physician should find another trusted adult in whom she could confide. And the importance of supportive

adult relationships should be emphasized in the follow-up visits.

A clear discussion about confidential care, between providers, patients and their families, is an essential part of anticipatory guidance as adolescence approaches. In addition to facilitating parents' understanding of their child's evolving health care needs, this discussion can diminish future conflict between a parent who wishes to be fully informed and a teenager who needs and wants to obtain confidential care. Furthermore, it may provide a backdrop for encouraging young patients to discuss their health care decisions with their parents as they grow older.

Summary

Jessica's case highlights many common ethical and legal challenges that providers face when caring for adolescent patients. Adolescence is a time of testing boundaries and expanding one's sense of autonomy. However, the ability to make well-considered decisions is still forming, and health care providers play an integral role in supporting adolescent patients as they face the unanticipated consequences of their choices. A thorough knowledge of the legal provisions or obstacles such patients face is of utmost importance to those caring for them, as the health care provider may be the only person these vulnerable patients can turn to. Additionally, the developmental needs of these patients must be understood, and efforts to foster supportive adult relationships should be encouraged. The primary obligation that providers have to deliver care to their patients should not overshadow the benefits of open communication between adolescents and their parents, whenever possible.

References

1. Feierman J, Lieberman D, Chu YR. Reproductive rights project. Teenagers, health care and the law: a guide to the laws on minors' rights in New York. New York: New York Civil Liberties Union; 1997.
2. Zuckerman v. Zuckerman, 536 N.Y.S.2d 666, 668 (App. Div. 2d Dept. 1989).
3. Gittleman v. Gittleman, 438 N.Y.S.2d 130, 132 (App. Div. 2d Dept. 1981).
4. New York State Public Health Law 2504.
5. Diaz A, Neal WP, Nucci AT, et al. Legal and ethical issues facing adolescent health care professionals. *Mt Sinai J Med* 2004; 71(3):181–185.
6. www.crlp.org/pub_fac_titlex2.html [accessed 6/14/05]
7. New York State Public Health Law 17.
8. New York State Public Health Law 2781 (1).
9. New York State Public Health Law 2130 (3).
10. 10 N.Y.C.R.R. 63.8(a) (3).
11. New York State Public Health Law 2780 (5).
12. New York State Public Health Law 2782 (4)(e)(2).
13. Ford CA, English A. Limiting confidentiality of adolescent health services: what are the risks? *JAMA* 2002; 288(6):752–753.
14. Rosen DS, Elster A, Hedberg V, Paperny D. Clinical preventive services for adolescents: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 1997; 21(3):203–214.
15. Diaz A, Boozang P, Lipson K, Bachrach D. Health insurance coverage of New York's adolescents: filling in the gaps. New York: Mount Sinai Adolescent Health Center and Manatt, Phelps and Phillips, LLP; 2004. Copies available by contacting corresponding author.
16. http://www.plannedparenthood.org/library/FAMILYPLANNING_ISSUES/TitleX_fact.html [accessed 6/14/05]
17. Piaget J, Inhelder B. The psychology of the child. Weaver H, translator. 1st ed. New York: Basic Books, Inc.; 1969. p. 130.
18. Turner RA, Irwin CE Jr., Tschann JM, Millstein SG. Autonomy, relatedness and initiation of health risk behaviors in early adolescence. *Health Psychol* 1993; 12(3):200–208.
19. Erikson E. Identity, youth and crisis. 1st ed. New York: W.W. Norton; 1968.
20. Steptoe A, Wardle J. Locus of control and health behaviour revisited: a multivariate analysis of young adults from 18 countries. *Brit J Psychol* 2001; 92(Pt 4):659–672.