

Virtual Mentor

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Confidentiality and Consent in Adolescent Substance Abuse: An Update

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Introduction

Privacy is essential to adolescents who seek health care. When adolescents perceive that health care services are not confidential, they report that they are less likely to seek care, particularly for reproductive health matters or substance abuse [1-8]. Clearly, delay or failure to receive care for these concerns increases the risk for complications [9].

Over the past 3 decades, our understanding of the cognitive development of adolescents and awareness of the prevalence of risk-taking behavior have led to an acceptance that we must provide confidential health services as an essential component of adolescent health care. In the United States, confidentiality, particularly with respect to sensitive issues such as reproductive health care and substance abuse, has become a well-established tradition, grounded in law, ethics, and clinical practice [10].

Legal framework

Until 50 years ago, parents had the legal right to make most decisions for their minor children. During the 1960s and 1970s, the Supreme Court established that minors have certain constitutional rights, including the right to privacy with respect to contraception and abortion [11]. During the 1970s, many states established laws that allowed minors to consent to treatment for sexually transmitted diseases [12], after it became clear that adolescent sexual activity was more widespread than previously believed. Most states subsequently added laws that allowed minors to consent to one or more of the following: alcohol and substance abuse treatment, mental health care, and contraception.

All states require parental consent for most medical care provided to minors, with several exceptions. One is provision of health care to the “emancipated minor,” generally understood to refer to the minor who is living apart from the parent and is financially independent. A minor may be considered emancipated if he or she is married, a parent, or in the military [13]. In general, an emancipated minor can consent to all health care.

Other exceptions include care for pregnancy, substance abuse, sexually transmitted diseases, mental illness, and provision of contraception. All states have laws which permit minors to consent to one or more of the listed services, but there is tremendous variability among state laws, and most states do not have laws for every situation. While state laws cover alcohol and drug abuse, some specify only one or the

other. Some states prohibit disclosure to parents, some leave this to the physician's discretion, and others require disclosure under certain circumstances. The Center for Adolescent Health and the Law recently published a compendium of state laws that address confidentiality and consent [14].

States Determine Confidentiality Rights of US Teens

The Health Insurance Portability and Accountability Act of 1996 (HIPAA), which took effect in 2002, protects confidentiality for minors under some circumstances. Parents (and guardians) have control over health information and access to it for nonemancipated minor children except in situations (like those described above) in which minors are legally able to consent to health care. This federal law, however, defers to state laws which either allow or prohibit disclosure of confidential information to parents or guardians [15,16]. If a state law requires a physician to disclose information to a parent, HIPAA allows the physician to do so. If a state law permits, but does not require, the physician to disclose information to a parent, HIPAA allows physician discretion on the matter. If state law prohibits disclosure of information to a parent, the physician may not disclose without the minor's permission. If there is no state law, a physician has discretion about disclosing to a parent who requests information [17].

Medical organizations such as the American Academy of Pediatrics, American Medical Association, American Academy of Family Physicians, American College of Obstetricians and Gynecologists, and Society for Adolescent Medicine all have endorsed policy recommendations on adolescent confidentiality [18,19].

Clinical Framework

As mentioned previously, studies show that adolescents are less likely to seek health care for sensitive issues if they believe that their parents will be informed. Many adolescents are unaware of their right to confidential care for certain services, and many report that they have never discussed confidentiality with a health care provider [1,6]. Many adolescents choose to involve their parents in important health care decisions. Among those who do not involve parents, many have experienced violence within the family, and they fear incurring violence if they were to try [20].

When treating adolescents, physicians should discuss confidentiality at a first visit with the patient and parents. Limits to confidentiality should be explained. Parents and patients need to understand that if the adolescent poses a threat to self or others, confidentiality may be broken. In such cases, the physician should explain that this would be discussed first with the adolescent. Billing policies, medical records, and appointment notification can compromise confidentiality. Physicians should be aware of this and explain the possible breaches of confidentiality to adolescent patients and their parents. All clinic staff should understand policies about confidentiality and consent.

When screening adolescents for risk-taking behaviors, physicians should interview them without a parent present. Interviewing the patient privately, even for a minor illness, can optimize opportunities to ask about risk-taking behaviors, including

substance abuse. Most physicians prefer to have adolescents communicate with parents and involve them in important health care decisions, but they recognize that within some relationships, parents' knowledge of substance use or sexual activity can hinder the minor's treatment and might lead to punishment or abuse.

Issues Related to Substance Abuse

A common question that arises when caring for minors with suspected or identified substance abuse is: when is it appropriate to perform urine drug testing without the adolescent's consent? An adolescent with impaired mental status or one who has been involved in trauma, violence, or overdose should be tested for drug use. Testing can be a useful tool to monitor drug use in adolescents during drug treatment or maintenance programs.

In clinical practice, physicians may encounter parents who suspect drug use and request a urine drug test with or without their adolescent's consent. When this occurs, the clinician should obtain more information about the parents' concerns, and they should be informed that a positive urine test does not give information about the drug use pattern, or presence of abuse or dependence [8]. Similarly, a negative test does not indicate that the patient has not used drugs.

The minor should be questioned alone, ideally with the clinician sharing information about the parent's concerns. Minors often consent to drug testing. For minors who refuse testing, it is rarely, if ever, appropriate to test, except in the emergency situations mentioned above. Whenever the minor agrees to testing, the physician must first develop a plan for disclosure of test results to both parents and a dolescent before ordering the test.

Another question often asked in relation to drug use is: when it is appropriate to screen select populations, such as athletes? In 1996 the American Academy of Pediatrics published a policy statement on testing for drugs commonly abused by children and adolescents that opposes involuntary testing of young people for such drugs [21]. In June 2002 the United States Supreme Court ruled that public schools have the authority to perform random drug tests on middle school and high school students participating in all extracurricular activities [22]. Although the White House Office of National Drug Control Policy (ONDCP) has published a guidebook designed to encourage schools to incorporate policies for all students [23], there has been controversy among physicians and other experts as to the utility of such testing as well as concerns about invasion of privacy [20]. There is little evidence of the effectiveness of school-based drug testing in the scientific literature [24, 25], and few schools have the staff or skills to implement costly testing. Interpretation of testing can also be complicated by false positives and validity questions that arise from the potential adulteration of specimens. It is anticipated that professional organizations will develop further policy statements to address the issue of rigorous scientific studies of the safety and efficacy of school-based testing

Summary

When screening and treating minors for sensitive health conditions such as substance

abuse, confidentiality should be honored whenever possible, and potential limits to confidentiality clearly explained in advance. Adolescents are able to consent to alcohol and drug treatment in most states, but involvement of the family is optimal in most cases.

References

1. Cheng T, Savageau JA, Sattler AL, Dewitt TG. Confidentiality in health care: a survey of knowledge, perceptions, and attitudes among high school students. *JAMA*. 1993;269:1404-1407.
2. Ford CA, Millstein S. Delivery of confidentiality assurances to adolescents by primary care physicians. *Arch Pediatr Adolesc Med*. 1997;151:505-509.
3. Ford CA, Bearman PS, Moody J. Foregone health care among adolescents. *JAMA*. 1999;282:2227-2234.
4. Ford CA, Millstein SC, Alpern BL, Irwin CE. Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. *JAMA*. 1997;278:1029-1034.
5. Marks A, Malizio J, Hoch J, et al. Assessment of health needs and willingness to utilize health care resources of adolescents in a suburban population. *J Pediatr*. 1983;102:456-460.
6. Thrall JS, McCloskey L, Ettner SL, et al. Confidentiality and adolescents' use of providers for health information and for pelvic exams. *Arch Pediatr Adolesc Med*. 2000;154:885-892.
7. Reddy DM, Fleming R, Swain C. Effect of mandatory parental notification on adolescent girls' use of sexual health care services. *JAMA*. 2002;288:710-714.
8. Klein JD, Wilson KM, McNulty M, Kappahn C, Collins KS. Access to medical care for adolescents: results from the 1997 Commonwealth Fund Survey of the health of adolescent girls. *J Adolesc Health*. 1999;25:120-130.
9. American Medical Association Council on Scientific Affairs. Confidential health services for adolescents. *JAMA*. 1993;269:1420-1424.
10. Ford CA, English A, Sigman G. Confidential health care for adolescents: position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 2004;35:160-167.
11. English A. Legal and ethical concerns. In: Friedman SB, Fisher M, Schonberg SK, Alderman EM, eds. *Comprehensive Adolescent Health Care*. 2nd ed. St. Louis, Mo: Mosby; 1998:109-113.
12. Oberman M. Minor rights and wrongs. *J Law Med Ethics*. 1996;24:127-138.
13. Sigman GS, O'Connor C. Exploration for physicians of the mature minor doctrine. *J Pediatr*. 1991;119:520-525.
14. English A, Kenney KE. *State Minor Consent Laws: A Summary*. 2nd ed. Chapel Hill, NC: Center for Adolescent Health and the Law; 2003.
15. Health Information Portability and Accountability Act, Final Rule. *65 Federal Register*. 82462. Office for Civil Rights, Department of Health and Human Services. Washington, DC; 2000.
16. Standards for privacy of individually identifiable health information. *67 Federal Register* 53182. Office for Civil Rights, Department of Health and Human Services. Washington, DC; 2002.

17. English A, Ford CA. The HIPAA privacy rule and adolescents: legal questions and clinical challenges. *Perspect Sex Reprod Health*. 2004;36:80-86.
18. Weddle M, Kokotailo P. Adolescent substance abuse: confidentiality and consent. *Pediatr Clin N Am*. 2002;49:301-315.
19. American Academy of Pediatrics. AAFP statement of policy on adolescent health care: American Academy of Family Physicians Web site. Available at: <http://www.aafp.org/x6613.xml>. Accessed December 21, 2004.
20. King NM, Cross AW. Moral and legal issues in screening for drug use in adolescents. *J Pediatr*. 1987;111:249-250.
21. American Academy of Pediatrics. Committee on Substance Abuse. Testing for drugs of abuse in children and adolescents. *Pediatrics*. 1996;98:305-307.
22. Board of Education of Independent School District No 92 of Pottawatomie County et al v Earls et al. 536 US 822 (2002).
23. Office of National Drug Control Policy. *What You Need to Know About Drug Testing in Schools*. Washington, DC: US Government Printing Office; 2002.
24. Goldberg L, Elliot DL, MacKinnon DP, et al. Drug testing athletes to prevent substance abuse: background and pilot study results of SATURN (Student Athlete Testing Using Random Notification) study. *J Adolesc Health*. 2003;32:16-25.
25. Yamaguchi R, Johnston LD, O'Malley PM. Relationship between student illicit drug use and school drug-testing policies. *J School Health*. 2003; 73:159-164.

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