Confidentiality and Consent in the Care of the Adolescent Patient

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Practice Gap

Confidentiality protections are critical in the provision of comprehensive primary care of adolescent patients. The protections differ based on state laws and are limited by electronic health record documentation and billing operations of individual physician practices. Physicians need to strive to increase their knowledge regarding confidentiality protections for their adolescent patients. Moreover, physicians should understand their role in preventing possible confidentiality breaches.

Objectives After completing this article, readers should be able to:

1. Define confidentiality, its limitations, and reasons for developmentally appropriate confidentiality protections for adolescents.
2. Recognize confidentiality protections for adolescents provided by state and federal laws, including the Health Insurance Portability and Privacy Act privacy rule.
3. Explain minor consent laws.
4. Describe the limitations and advantages of the electronic health record in providing confidentiality protections.
5. Identify concerns and solutions related to billing for confidential services.

CASE

A 16-year-old girl who has been your patient since birth presents to an appointment alone and requests testing for sexually transmitted diseases (STDs). She also does not want her parents to find out about this visit. How would you proceed?

Confidentiality and Autonomy

The provision of confidentiality and the ability of adolescents to consent for certain health concerns are the cornerstone of optimal adolescent health-care. (1) According to this tenet, information about an adolescent’s health-care is not disclosed without his or her permission. Assurance of confidentiality is important to protect the adolescent’s health and to safeguard public health. The major causes

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ABBREVIATIONS

CDC Centers for Disease Control and Prevention
EHR electronic health record
EOB explanation of benefits
HIPAA Health Insurance Portability and Privacy Act
HIV human immunodeficiency virus
SAHM Society for Adolescent Health and Medicine
STD sexually transmitted disease
of morbidity and mortality in adolescents are due to risky behaviors such as sexual activity and alcohol and substance use, as well as unmet mental health needs.

During the past 3 decades, research has supported the importance of the provision of confidential health-care and illustrated that if not provided, adolescents and young adults will not seek out prescription contraceptives, receive screening and treatment for STDs, or disclose substance use to the providers at their medical home. (2)(4)(5)(6) Moreover, they will withhold information from their health-care provider and may not return for subsequent visits. (7) During the adolescent years, adolescents transition from children to adults, and clinicians need to support the adolescent’s individualization and developing autonomy. By ensuring confidentiality for certain health-care concerns, pediatricians are supporting this crucial milestone of adolescent development by fostering decision-making skills. This approach also reflects the physician’s ethical obligation to ensure the patient’s well-being and protect the nonautonomous. Because we wish to minimize harm, the ethical concept of beneficence is also in play when providing confidential care. Beneficence refers to the clinician’s responsibility to prioritize the patient’s well-being when making decisions about medical care. Therefore, the services that may be provided confidentially to adolescents are related to reproductive health, outpatient substance abuse, and mental health services.

For more than a quarter of a century, national medical organizations, including the American Academy of Pediatrics, the Society for Adolescent Health and Medicine (SAHM), the American Academy of Family Practice, and the American College of Obstetricians and Gynecologists have supported the need to provide confidential care for adolescents (Table 1). (8)(9)(10)(11) Not only do they call for such care, but they also advocate for education of adolescents and their parents about the importance of confidentiality, particularly for evaluation, testing, and treatment of STDs (including human immunodeficiency virus [HIV]), preventive reproductive health-care, contraception, and pregnancy-related services such as abortion.

It is essential to educate families, both parents/guardians and adolescents, on the reasons for clinicians requesting to spend part of the visit with the adolescent alone and starting to do this annually in early adolescence as part of best practices. Adolescents are frequently unaware of where they could obtain confidential services, especially substance abuse and mental health services, and do not use or envision their primary care providers as a resource. (12) The 11-year-old visit, when multiple vaccines are recommended and many children are on the brink of entering middle school, is a good time to start to engage in this conversation with parents and their preteens. Physicians should have discussions with the parent or guardian and the preteen or adolescent on the importance of adolescents having time alone with their physicians so that adolescents can voice their concerns to physicians and be encouraged to take responsibility for their health-care decisions. Physicians should continue to encourage open communication and discussions surrounding sensitive topics between parents and adolescents.

Primary care offices could create office policies describing adolescents’ rights and share them with all new patients and families of preteens so as to normalize this essential aspect of adolescent health-care. This office culture should allow for improved trust and the potential for disclosures by adolescents and their parents. The SAHM recommends the

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EHR = electronic health record.
training of front desk and billing staff so that they could provide appropriate guidance to patients on the confidential services available in their office. (9)

The ability of an adolescent to interpret health-care information provided to them and to adhere to recommendations is related to their cognitive development. The maturation of the adolescent brain generally occurs as the teen progresses from early to late adolescence. (13) Similar to physical pubertal changes, cognitive changes of adolescents are not age dependent and, therefore, age is not the determining factor in the adolescent’s ability to make health-care decisions. Cognitive development advances as the adolescent progresses through early, middle, and late adolescence (Table 2). After age 18 years, adolescents have full legal rights as they become legal adults and are considered to have full adult reasoning. Parents may have or may apply for legal guardianship of their adult children with intellectual disabilities and, therefore, would have the power of attorney to make medical decisions for their adult child. It is less common, but possible, that parents are able to obtain legal guardianship of their adult children with mental health problems.

Intellectual abilities should also be considered when making the determination of capacity to consent. Depending on the level of intellectual disability, many adolescents cannot consent to treatment based on their capacity to understand the risks, benefits, and alternatives of the confidential services. These adolescents have to be evaluated by a physician to assess for their capacity to understand pros, cons, and alternatives for the treatments offered. Frequently, parents continue to be involved in reproductive decisions for adolescents with intellectual disabilities.

The degree of autonomy that the adolescent possesses is also crucial in determining the adolescent’s competence to consent. By giving the adolescent the ability to make his or her own health-care decisions, the provider is supporting the adolescent’s growth as a health consumer.

Relevant Legal Status Laws
Under the law, an adolescent younger than 18 years is generally considered a minor. However, minors younger than 18 years may have acquired legal status under one of the following provisions: mature minor, emancipated minor, incarcerated minor, or a minor in foster care. If a minor’s status has been designated as any of these, they may be afforded some of the same legal rights as adults, and this affects their right to obtain confidential health-care.

Mature Minor. A mature minor is generally a minor who has sufficient intellect and autonomy to provide informed consent for medical care. When determining whether an adolescent is a mature minor, one must consider chronological age and developmental maturity, degree of autonomy, ability to adhere to medical care, and the seriousness of the illness versus risks of therapy. Clinicians need to evaluate whether a minor has the capacity to make voluntary decisions and weigh alternatives. For example, if the adolescent has been able to manage previous illnesses and adhere to medications/treatment, then the minor can be deemed competent to consent to their care if state law allows. However, minors generally cannot receive care for routine, nonemergent general health-care without parental consent.

Emancipated Minor. Emancipation, under the law, is defined as a surrender of parental rights to a child. Each state has laws defining circumstances where a minor may be considered emancipated. (14) Such circumstances may include a minor who is married, lives away from parents or legal guardians, is financially independent, is in the military, or whose parent/guardian has renounced their parental rights.

Pregnant and Parenting Teens. Pregnant teens can consent to their own health-care in most states, as well as that of their child. Questions do come up around the rights of teen fathers. Generally, if a teen is listed as the father of a child on the birth certificate, he would have the same parental rights.

<table>
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<th>TABLE 2. Adolescent Development</th>
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<td><strong>DEVELOPMENTAL STAGE</strong></td>
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as the teen mother. However, it is quite variable as to whether a parenting teen can consent for their own health-care, unless it falls into the categories listed previously herein. Providers should reference the laws in their states.

**Teens in Foster Care.** Many states continue to allow parents or legal guardians to consent for medical treatment of their children after the children have entered into foster care. To streamline the consent procedure, many foster agencies have the parents sign a consent form for routine services, which is available from the child’s welfare worker. (15) For teens whose parents are not available or not cooperative, courts make decisions to appoint a guardian or have the welfare commissioner provide consent for services outside of routine care, such as psychotropic medication prescription or surgical procedures. If a teen in foster care requires emergency medical attention and a legal guardian is not available, a physician could provide services without parental consent if their state law allows this. Teens in foster care could consent to confidential services based on their state laws similar to other teens residing in their states and if they have the capacity to consent.

**Relevant Federal and State Laws**

Another important consideration when determining the possibility of ensuring confidential health-care for minor adolescents are federal and state laws that govern the minor’s ability to consent for medical treatment. Federal laws override state laws and, therefore, basic knowledge of both is necessary to decide on the services that could be offered to the adolescent without parental consent (Fig).

**Federal Laws.** There are few federal laws related to the provision of confidential health-care. A federal privacy rule was established in 2002, based on the 1996 Health Insurance Portability and Privacy Act (HIPAA) to allow the minor children to access their health information if it is related to confidential services or if they receive court approval to obtain those services and, therefore, have authority over their medical records. Parents cannot access these records unless permitted by their minor child (Table 3). (3)

Furthermore, the federal privacy rule ensures confidentiality for all health information to patients 18 years or older. (16) It is important to remember that for these patients, all health information must be kept private from parents, unless the adult child consents to disclosure of their health information. Health-care providers sometimes overlook this point because they have cared for the patient throughout childhood and are accustomed to the parent overseeing the child’s health-care. The parents of adult children need to be educated about HIPAA, as do the adult children.

Title X of the Public Health Service Act is federal legislation that provides grants to organizations to assist with family planning and related preventive health services and requires programs that it funds to provide confidential services for adolescents. (17)(18) Similar rules exist for federally supported substance and alcohol use programs which receive grant funding and review by the Substance Abuse and Mental Health Services Administration. (19) Recipients of Medicaid insurance also have specific federal laws that require confidential protections for adolescents and are used to prevent confidentiality breaches. The HIPAA privacy rules defer to federal law surrounding these programs.

**State Laws.** Laws around adolescent confidentiality are generally state specific and may be complex. A variety of states give physicians permission to disclose information to parents or guardians that could be considered confidential, such as treatment for STDs. State laws often reflect legislation but also could be based on case law of the courts and statutes. These laws often weigh the tenets of family law (the status of minor children and the responsibilities and rights of parents/guardians) against the rights of the individual.

Most states have laws ensuring confidential care for minors based on the type of medical services requested, specifically, sexual health (STDs, contraception, pregnancy, and pregnancy options), outpatient mental health, outpatient...
alcohol and substance abuse, and diagnosis and treatment for sexual assault. (20) These laws are based on the need for privacy inherent to these categories of health-care, as well as the normative adolescent development of autonomy, as described previously herein. All states, generally, allow for the provision of confidential services for minor adolescents for the prevention, screening, diagnosis, and treatment of STDs and sexual assault. There may be exceptions related to the screening, prevention, and treatment of HIV infection and AIDS, as well as vaccinations (human papillomavirus, hepatitis B, hepatitis A). Most states require parental consent for treatment of HIV/AIDS, as well as immunizations. The minor’s permissibility to access confidential care for contraception, prenatal care, care for their own child, mental health, and outpatient alcohol and substance abuse varies among states but in many cases is permissible, albeit with some restrictions. Only 2 states and the District of Columbia allow minors to consent for termination of pregnancy. If a state does not allow a minor to consent to termination of a pregnancy, a system of judicial bypass must exist so that a minor may petition the court for the ability to consent for termination of pregnancy. This may be a difficult process for an adolescent and requires access to a legal advocate and psychosocial support. The Alan Guttmacher Institute maintains a current listing, by state, of what reproductive health-care services may be provided confidentially. (20)

**Privacy of Health Information**

**Exceptions to Confidentiality.** There are circumstances when a minor’s confidentiality cannot be maintained and the health-care provider is mandated to disclose private information. Providers must be aware of their state’s legal requirements, such as reporting child abuse. Clinical and professional judgment is essential when assessing patients for abuse and exploitation. Moreover, if an adolescent is deemed to be harmful to self or others, confidentiality must be broken. It is essential that these limits of the provision of confidential health-care be discussed with adolescents and parents/guardians as part of the general discussion on adolescent confidentiality.

Another exception to the assurance of confidentiality is the diagnosis of STDs such as gonorrhea, chlamydia, syphilis, and HIV that are in the category of reportable diseases.

### TABLE 3. Resources with Information on Federal and State Laws on Confidentiality

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<th>RESOURCE</th>
<th>WEBSITE</th>
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<tr>
<td>Centers for Disease Control and Prevention. HIPAA privacy rule and public health: guidance from CDC and the U.S. Department of Health and Human Services.</td>
<td><a href="https://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm">https://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm</a></td>
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<td>Electronic Code of Federal Regulations.</td>
<td><a href="https://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&amp;sid=b7e8d29be4a2b815c404988e29c06a3e&amp;rgn=dv3&amp;view=text&amp;node=42:1.0.1.1.2&amp;idno=42%20-%20se42.1.2.114">https://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&amp;sid=b7e8d29be4a2b815c404988e29c06a3e&amp;rgn=dv3&amp;view=text&amp;node=42:1.0.1.1.2&amp;idno=42%20-%20se42.1.2.114</a></td>
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<tr>
<td>Policy Compendium on Confidential Health Services for Adolescents. 2nd ed.</td>
<td><a href="http://www.cahl.org/PDFs/PolicyCompendium/PolicyCompendium.pdf">http://www.cahl.org/PDFs/PolicyCompendium/PolicyCompendium.pdf</a></td>
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It is required that positive results are reported to local departments of health and, ultimately, the Centers for Disease Control and Prevention (CDC). This is in the interest of public health and allows the health department to assist in the notification and treatment of sexual partners so that these infections become less transmissible to the general population.

Additionally, there is no authorization required for the automatic release of information to health insurance plans or health-care providers who are involved in the care of the patient. (3)(22)

**Electronic Health Record.** Adolescents and young adults have the highest rate of Internet use and, therefore, are most likely to benefit from medical information becoming available electronically. (23) They are also the group that needs the most protection in this electronic generation. In 2009, the Health Information Technology for Economic and Clinical Health Act was issued by the US Department of Health and Human Services to increase HIPAA protections and improve the delivery of healthcare through health information technology use. (24) This has led to a more widespread use of electronic health records (EHRs), which are systems that allow the sharing of information within a health-care organization and include clinical visit notes, test results, and problem and/or medication lists. In 2012, almost 4 of every 5 pediatricians were using an EHR. (25) The American Academy of Pediatrics, SAHM, and American College of Obstetricians and Gynecologists have published policy statements emphasizing the importance of adolescent confidentiality protections in EHRs and advised that the protections should be guided by the established federal and state laws (Table 3). (26)(27)(28)

An additional challenge to the provision of adolescent confidential services has been the rollout of the meaningful use requirements by the Centers for Medicare and Medicaid Services in the Department of Health and Human Services in 2010. Meaningful use requirements are used to monitor health providers’ improvements in EHR utilization and are used for reimbursement purposes. (29) One of the requirements is the provision of a clinical summary printout after each medical visit. In the case of an adolescent who comes in with a parent and is seen for part of the visit alone, some of the laboratory tests, medications ordered, and problems added to the problem list could pose a risk to confidentiality protections. Strategies that could be used to prevent breaches in confidentiality include the restriction of the confidential diagnoses, medications, and laboratory tests from the clinical summary printout for adolescents younger than 18 years and distribution of the summary directly to patients older than 18 years.

Another meaningful use requirement is to allow patients or their representatives access to a secure Internet portal that contains their health information, including diagnostic test results, problem lists, and medications and/or opportunity to communicate with their physicians through a secure e-mail. This provides a challenge to protection of confidentiality, while also being an important tool that could be set up to allow for direct and improved communication between adolescents and their providers.

In their position paper, the SAHM recommends that medical providers be aware of their current EHR settings and actively advocate and improve protections for adolescents in their health-care system. (28) The SAHM also suggests the development of separate portals for adolescents and their parents, with limited exceptions for adolescents with serious medical illnesses and those with intellectual disabilities. An additional recommendation is the distinction between health information exchanges, which are designed to allow for medical information sharing between medical facilities, and the EHR, located in a single medical system. At the time of health information exchange creation, settings should be incorporated to prevent the release of sensitive information to other medical centers unless directly approved by the adolescent so that this information is not inadvertently shared with parents. (28)

Additionally, the automated reminder service that has been introduced by many pharmacies for patient convenience could pose a risk to confidentiality for adolescents and should be discussed at the time of medication prescription. (30) Possible solutions include providers offering teens the option of speaking with their parents about the medication being prescribed, checking with the pharmacy regarding their use of automated reminders, or sending the prescription to a different pharmacy than the one used by the family.

**Billing.** If an adolescent chooses to obtain confidential services, he or she needs to be aware of the possible breaches to confidentiality at the time of billing and payment by their health insurer. Explanation of benefits (EOB) is a letter that is mailed to the primary insurance policyholder, generally the parents, at the time of the payment for the claim and includes information about the person who received the medical services and the services obtained during that visit. The intention of the EOB letter is to prevent billing fraud and provide patients with detailed information about what was paid by the insurance policy and what is the financial responsibility of the policyholder. (31) For adolescents, EOB
letters could disclose sensitive information to their parents. Some states have started to address this issue in their insurance law in an attempt to prevent EOBs from being mailed out for certain, confidential services, with the modification of the law to include the opportunity for confidential communication. Confidential communication refers to the ability of owners of health information to ask for the EOB to not be mailed or to be sent by an alternative means, such as e-mail. California was the first state to enact this law, which went into effect in 2015. Similar laws/regulations are pending or have been approved into law in Oregon, Massachusetts, Maryland, and Washington. New York has enacted a law that has removed the requirement for the EOB to be sent if only a copayment was required that was paid at the time of the visit and the claim is fully paid, unless requested by the policyholder. (32)

The laws preventing release of EOBs are relatively new and not all-encompassing, so adolescents need to be educated about this possibility of breach of their confidentiality in the case of an EOB being mailed to their home, and adolescents should be counseled about alternative ways of obtaining confidential services. Many college health services and school-based clinics provide low cost or free care for reproductive, mental health, and substance abuse services. In addition, Title X–funded health programs, including Planned Parenthood, are centers where adolescents may obtain confidential screening for STDs and contraceptive management without billing concerns. Another alternative is a subsidized health insurance plan for family planning services that is available in 20 states in the United States as an expansion of Medicaid services. (33) Other options include the provision of reduced cost visits, or adolescents could be offered to pay for the services out of pocket to avoid the EOB letter.

Summary

For the 16-year-old girl who is requesting sexually transmitted disease (STD) testing:

- Based on evidence quality D, all states allow for confidential STD testing, but there are some states that may require the physician to disclose to parents any positive results, and you will need to reflect on the laws guiding practices in your state.

- Based on evidence quality D, she should be notified about the possibility of an explanation of benefits letter being sent to her home because of office billing and laboratory testing, thus possibly disclosing some sensitive information, and she should be notified of the alternative ways available for her to pay for these services, including information on how to obtain a subsidized health insurance plan if available in your state to maintain confidentiality.

- Based on evidence quality D, if your state does not offer subsidized health insurance plans you may need to refer her to Planned Parenthood or a public health clinic. Alternatively, you can counsel her on having her partner share some of the cost of her laboratory testing and subsidize the fee for her office visit.

- Based on evidence quality D, ensure that your office electronic health record has protections for adolescents and that no sensitive diagnoses, tests, or medications are printed on the after-visit summaries that could be easily seen by her parents. Moreover, ensure that you have designed your patient portal to disable release of laboratory results of adolescents younger than 18 years.

- Based on evidence quality D, with all these safeguards, you are able to assure your minor adolescent patient that her sensitive information will not be released to her parents without her permission. You encourage her to discuss her health with her parents. However, if she cannot, you can still provide confidential care for her reproductive and mental health.

References for this article are at http://pedsinreview.aappublications.org/content/40/10/508.
1. A 16-year-old girl presents to the emergency department (ED) after sustaining a left ankle injury while playing basketball. Physical examination reveals a swollen left ankle. She is unable to bear weight. The initial impression is that this is likely a sprain, but a fracture cannot be ruled out. A urine pregnancy test is ordered before obtaining a radiograph. The ED physician receives a telephone call from the laboratory that her urine pregnancy test result is positive, and radiography is deferred. Which of the following is the ED physician’s next best step in the management of this patient?
   A. Call her mother and notify her that her daughter is pregnant.
   B. Call her mother and ask her to have the patient call the physician back.
   C. Call her mother and ask her to follow up with the ED physician the next day and give her the pregnancy test results of her daughter in person.
   D. Break the news only to the patient, and encourage her to discuss the results with her mother.
   E. Send the patient to her pediatrician without giving her the results.

2. A 14-year-old girl is brought to the clinic by her mother after getting a call from school that she is skipping classes to be with her 21-year-old boyfriend. The mother is worried that her daughter is having sex. When interviewed alone, the patient seems withdrawn but denies everything. In addition to testing her for pregnancy, which of the following is the most appropriate next step in the management of this patient?
   A. Tell the patient with the mother in the room that a sexual relationship between a 21-year-old and a 14-year-old is illegal in your state and refer her for counseling.
   B. Send her to the ED to get a sexual assault examination because she is younger than 16 years and you are concerned about statutory rape.
   C. Refer her to the child abuse center for further evaluation.
   D. No follow-up is needed because the child denies everything.
   E. Call the clinic social worker and discuss the best option for the patient according to state laws.

3. A 17-year-old young man comes to the school clinic for a follow-up from a previous clinic visit to discuss positive results on sexually transmitted disease testing. He is positive for gonorrhea. He is in a boarding school where he lives alone in the dormitory. His parents live overseas where his father works. He has had a steady 16-year-old girlfriend for the past 6 months. You note that he is on his father’s insurance plan. Which of the following is the most appropriate next step in management?
   A. Notify his parents of his laboratory results and withhold treatment until the parents give consent because he is a minor (<18 years of age).
   B. Report his results to the health department while waiting for his parental consent to treat.
   C. Treat him because he is considered an emancipated minor; reporting to the health department is not required.
   D. Treat him because he is considered an emancipated minor, treat his partner, report it to the health department, and counsel him that despite confidential billing his father can find out from the insurance bill.
   E. Treat him because he is considered emancipated minor, report it to the health department, and counsel him that because of confidential billing his parents will never know.

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4. A 2-month-old boy is brought to the clinic by his 16-year-old mother for his 2-month health supervision visit. The mother is accompanied today by the boy’s maternal grandmother. Both parents are 16 years old, and they live with the maternal grandparents. The 2-month-old boy is due today for his first set of vaccines. Which of the following is the most appropriate plan regarding the consent for the required vaccines in this patient?
   A. Consent is required and needs to be given by the father.
   B. Consent is required and needs to be given by both grandparents because the parents are living with them.
   C. Consent is required and the 16-year-old mother can give consent for her child’s vaccines.
   D. Consent is required and should be given by the maternal grandmother because the mother is only 16 years old.
   E. No consent is required because this is a routine office procedure and is covered under consent to treat.

5. A 14-year-old boy is brought to the ED with severe headaches and sleeping a lot. Mom reports that he has not been wanting to get out of bed and has missed a week of school. The patient is interviewed alone. Initial assessment in the ED shows a young man with depressive mood; he reports constant crying while alone, inability to sleep, and wishes to die. He reports that he has been depressed for months and recently his depressive symptoms have worsened after his uncle, whom he was close to, died a few weeks ago. He feels that life is not worth living anymore and is contemplating ways to kill himself. He asks not to tell his parents because they have been through a lot of family stressors lately. Which of the following in the next best step in the management of this patient?
   A. Arrange for a psychiatry outpatient appointment in 5 to 7 days.
   B. Respect the patient’s confidentiality if he signs a contract promising not to kill himself.
   C. Have the patient follow up with his primary care physician.
   D. Inform him that you have to tell his parents, activate an emergency detention order, and admit the patient to an inpatient psychiatric center for evaluation and clearance.
   E. Prescribe him tricyclic antidepressants and have him follow up with his pediatrician.
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