Complexities in HIV Consent in Adolescents

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Summary: A large proportion of people infected with the human immunodeficiency virus (HIV) are adolescents. Unfortunately, there is no uniform policy on minors' rights to consent to HIV testing and treatment. The process of obtaining consent is complex and depends on several factors, including individual state HIV laws and laws relating to a minor's capacity to consent to general health care. These issues are particularly relevant given the growth of HIV in this population. In this review, the complex laws of informed consent and confidentiality surrounding HIV disease in adolescents are reviewed. Familiarity with these laws by the clinician is essential to halting the HIV epidemic in adolescents and will be underscored. *Clin Pediatr.* 2005;44:473-478

Introduction

Children and young people are at the core of the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) epidemic.[1] Worldwide, approximately 5 million people were newly infected with HIV in the year 2004.[2] Adolescents and young adults ages 15 to 24 years comprise greater than half of those involved.[3] An estimated 6,000 young people in this age group become infected with HIV daily.[3] Sadly, 90% of people with HIV worldwide are unaware of their status.[3] In the United States, approximately 16% of youths living with HIV are cognizant of their HIV status, compared with two thirds of infected adults.[4]

Generally, patients 18 years or older can consent to their own health care, including HIV testing and treatment. On the other hand, parental consent is usually required by law to provide medical care to a minor, i.e., a person under 18 years of age.[5] Many states' laws, however, permit a minor, who can give informed consent, to consent to medical treatment in certain circumstances. In the case of HIV testing and treatment, some states have specific laws that address the ability of a minor to consent.

A minor may face barriers and difficulties regarding HIV testing and medical care. Overcoming these barriers may be important to halting the epidemic of HIV/AIDS. In this review, we discuss the important issues involved in HIV testing and treatment for minors, including issues of informed consent for testing and treatment, confidentiality and disclosure. We review the clinical implications of the laws involved and highlight the need for health care professionals to be knowledgeable about these issues.

Clinical Scenarios

Consent for HIV Testing in an Adolescent

A health care provider may reflexively approach a parent for consent for HIV testing of an adolescent child.

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Case: A 15-year-old adolescent male who resides in New York State informs his pediatrician that he thinks he may be HIV positive after having unprotected sex with a HIV-positive partner and would like to be tested. The pediatrician who has provided medical care to this patient for the previous 15 years may struggle with the decision as to who should give consent for HIV testing (the adolescent or the parent) and to whom to disclose the result. However, there are important implications associated with parental notification. Several studies have indicated that adolescents have concerns about confidentiality that restrict their utilization of medical care. A study by Klein and colleagues indicated that 35% of students reported that parental notification was one reason for not seeking medical care.[6] A higher percentage of adolescents report that they would abstain from care for contraception, sexually transmitted infections, or substance use due to fears about parental notification.[7] Recently, Reddy and colleagues examined the potential outcomes of mandated parental notification for prescriptive oral contraception on use of sexual health care services by adolescent females.[8] Fifty-nine percent reported that they would discontinue using all sexual health care services, postpone testing or treatment for HIV or other sexually transmitted diseases (STDs), or cease use of specific (but not all) sexual health care services if parents were notified about their seeking prescribed birth control pills or devices. Eleven percent suggested that they would terminate or delay STD testing or treatment, although the survey clearly stated that mandatory parental notification would only be limited to prescribed contraceptives.[8] Thus, these results suggest that the consequences of mandatory parental notification may not only increase adolescent pregnancies and births, but also increase rates of STDs[8] and HIV infection via vertical and horizontal transmission. Some possible reasons for these findings may be the adolescent's fear of a negative reaction by their parents, such as disapproval, rejection, or violence.[9,10]

The process of obtaining informed consent for HIV testing from a minor hinges on several factors, including state HIV or HIV-related consent laws and the legal status of minors in those states regarding health care decision-making in general.[5] In most cases, under the law, patients who are 18 years or older can consent to their own health care. For patients younger than 18 years of age, parental consent is usually legally necessary to provide medical care.[5] However, in circumstances of HIV testing and treatment, a minor may have the right to make this decision on his or her own and should be afforded this opportunity.

Some states may provide a basis for testing under laws that permit a minor to consent to testing for STDs or reportable diseases. In these states, the definition of a STD or a reportable disease specifically includes HIV infection and the statutes allow minors the autonomy to undergo testing for STDs without parental notification.[5,9] In contrast, other states that do not include HIV infection under these statutes may have a separate law that specifically addresses HIV.[9]

States may have laws specific to the types of health services that may allow minors to give consent to HIV testing.[5] For example, most states have laws that allow minors to consent to care related to pregnancy, alcohol and substance abuse, mental health,[5] and emergency situations.[11] Furthermore, the United States Supreme Court has determined that the constitutional right of privacy protects minors in issues associated with contraception.[12,13] Under Title X of the Public Health Service Act, minors are entitled to family planning services in federally funded Title X family planning programs.[5,11] Since HIV testing has become an essential component of family planning services, several of these regulations may allow minors to give consent to HIV testing.[5]

Another factor on which informed consent depends is the legal status of the minor. Some states acknowledge an emancipated minor as one who can consent to medical testing and treatment without parental consent.[5,13] The definition of emancipated minors varies from state to state. Minors who are or have been married, self-supporting, in the armed services, parents themselves, or acknowledged by court to be emancipated are commonly considered emancipated by individual state laws and minors in these categories are permitted to give informed consent for their health care.[5,11,13-15] Some states may also impose a minimal age requirement for emancipation.[11,13]

Another category of minors who may consent to their own health care in some states is the mature minor.[5,11,13] A mature minor is one who is deemed sufficiently intelligent and mature enough to give informed consent. In other words, they have decision-making capacity. Some states have enacted mature minor statutes that allow mature minors to consent to their own medical care without parental consent.[11] Other states recognize this doc-

trine in common law. Statutes exist in certain states allowing other groups of minors to consent to his or her care. These categories include married minors, minors who are parents, pregnant minors, and homeless and runaway minors.[5,11]

Regardless of the circumstance giving the minor a basis to consent to an HIV test, the minor must be able to give informed consent, as with all patients who seek medical care. Informed consent means that the minor must be able to understand the condition, the nature and purpose as well as the risks and benefits of the proposed and alternative treatment, and that consent is voluntary.

For the adolescent who requested HIV testing in New York State, if the adolescent's treating physician determined the patient had the capacity to consent, the patient could consent to or refuse confidential HIV testing. Capacity to consent for HIV is defined in New York Public Health Law as the "individual's ability, determined without regard to the individual's age, to understand and appreciate the nature and consequences of a proposed health care service, treatment, or procedure, or of a proposed disclosure of confidential HIV-related information, and to make an informed decision concerning the service, treatment, procedure or disclosure."[16] If the minor is deemed to have capacity to consent, parental consent is not required. In fact, once the provider has made an individualized assessment and concluded that the minor has capacity to consent, he or she alone has the right to consent or refuse to consent to HIV testing.[12,16,17] Thus, the physician could only obtain consent for HIV testing from the adolescent.

N.Y. Public Health Law Section 2780 defines "confidential HIV related information" as "any information concerning whether an individual has been the subject of an HIV related test, or has HIV infection, HIV related illness or AIDS, or information which identifies or could reasonably identify an individual as having one or more of such conditions." Such information may not be disclosed to the parents of a minor without the minor's consent, after the minor has been deemed to have capacity to consent. An exception to this rule is that after counseling about the need for disclosure of HIV related information, a physician in New York may disclose such information about a minor if the physician believes that disclosure is medically necessary for timely care and treatment; provided, however, if in the physician's judgment disclosure would not be in the minor's best interest, the physician may withhold such disclosure.[18] A minor who has authorized capacity to make health care decisions, i.e., a married minor, a minor who is a parent, or a pregnant minor making decisions about prenatal care has the ultimate right to make testing and treatment decisions.[19] A physician may not disclose test results to such a minor's parent or legal guardian.[18,19] Thus, the adolescent's parent cannot be approached if the physician deemed the adolescent to have capacity to consent to testing.

Unfortunately, the laws surrounding HIV testing and consent are heterogeneous and are unique to each state. If the same patient presented in Iowa, he could consent to HIV testing, but the treating facility would be required to inform his mother if he tested positive.[4,20] This law may deter those minors that are at highest risk for HIV infection from seeking testing. In contrast, in other states such as Washington, the law allows minors the autonomy to be tested, and prohibits health care providers from informing parents of the test results.[4,21] In Colorado, the burden is placed upon the health care provider to determine whether a minor's parents or legal guardian may be informed of the test results. There, minors may consent to testing, but if the minor is younger than 16 years of age or not emancipated, the parents or legal guardian may be informed.[4,22]

Variability in state laws on minors' authority to consent to testing for HIV has been reported.[23] All states and the District of Columbia permit minors to consent to STD services.[23] However, some states have a minimum age requirement. A minimum of 43 states allow minors to consent for HIV/AIDS testing and/or treatment on the basis of a separate HIV/AIDS statute or by categorizing HIV or AIDS as an STD or a reportable disease.[24] A physician may inform a minor's parents that he or she is seeking or obtaining STD services in some states.[25] Parental notification is not required in any state except in Iowa, where a parent must be informed of a positive HIV test result.[25] What all this translates to is that every health care provider needs to be knowledgeable about his or her state laws regarding consent for HIV testing and how parental disclosure is handled.

Consent for HIV Treatment in an Adolescent

In clinical practice, a health care provider may be faced with issues related to not only consent to HIV testing, but also consent to HIV treatment in minors.

Case: A 16-year-old female has recently become sexually active, a major area of conflict between her and her mother. The adolescent informs her pediatrician that she fears her mother will disown her, as her mother had previously done with her sister, if her mother became aware of her sexual activity. She requests that her mother not be notified if she tests positive for HIV and states that she is willing to obtain treatment. If this 16-year-old female after consenting to HIV testing now tests positive, can she consent to her own treatment? Will the physician have to inform her mother?

As with the case regarding HIV testing, the process of obtaining informed consent for treatment depends on several factors, including the same state HIV-related consent laws, status of minors and other important factors. All states have not clearly classified HIV infection as a condition for which a minor has a right to consent to treatment without parental consent.[15] Most states that categorize HIV as an STD or reportable disease, and include HIV infection within such statutes permit minors to consent to HIV/AIDS treatment.[5] On the other hand, in those states that do not classify HIV infection as an STD, but have a separate HIV law, state-to-state variability exists regarding a minor's right to consent to HIV/AIDS treatment. Among those states with HIV-specific laws that permit minors to consent to HIV testing, only some explicitly permit minors to consent to HIV/AIDS treatment.[5,9] In fact, some states that permit adolescents to consent to HIV testing do not allow these young people to independently obtain treatment.[9] Other states have laws that authorize minors to consent to emergency care, pregnancy-related care, reproductive health services, and substance abuse treatment. A minor's right to HIV treatment might fall within these categories.

As with the factors of the minor's status that determine the right of minors to consent to HIV testing, the same holds true with regard to HIV/AIDS treatment. Thus, in states that have statutes or common law regarding emancipated minors and mature minors, minors fulfilling these criteria may consent to HIV/AIDS treatment.[5,11] Certain states with statutes that allow other groups of minors, such as minor parents, married minors, or runaway minors to consent to his or her care do authorize minors to consent to HIV/AIDS treatment.[5]

Again, the appropriate management of this minor depends on the state that the patient presented in. For example, in New York State, a minor's right to HIV treatment is not clearly defined. There is no explicit provision in statutes permitting minors to consent to HIV treatment. However, some advocates find a basis for minors to consent to HIV treatment in that "in emergencies, or cases when parental involvement is impossible or could cause harm, a minor who can adhere to the treatment can consent to care."[12] Under N.Y. Public Health Law § 2504, currently or previously married minors and parenting minors can consent to their own care, including HIV treatment. If HIV treatment relates to prenatal care, a pregnant minor can also consent to the treatment. Furthermore, public health statutes allow for minors to consent to treatment of certain illnesses, in particular STDs, without parental notification or consent.[26] Thus, while there is no explicit provision addressing consent for HIV treatment, advocates argue that there is basis for a physician to seek consent from minors for HIV treatment in New York.[12] On the other hand, minors in Colorado may consent to treatment and the consent of the parent or guardian is not a prerequisite for treatment.[27] However, if the minor is younger than 16 years of age or not emancipated, the parents or guardian may be informed of consultation, examination, and treatment.[27]

Disclosure in Occupational Exposure

A health care provider may be confronted with other disclosure issues.

Case: A 15-year-old male who has multiple sexual partners consents to HIV testing and in the process of drawing blood a nurse sustains a needle stick injury. Can the results be disclosed to the nurse who was occupationally exposed? In other words, does the nurse have a right to the test results? In New York, while a nurse cannot demand that a patient be HIV tested, she can request a test. If the minor consents to the test, the HIV status of the index patient may be revealed to individuals who were occupationally exposed in defined conditions.[28] This disclosure does not include the name of the index case, although it may already be known to the exposed individual.[28] Thus, the nurse is entitled to the adolescent's HIV test result. Again, every health care provider should become familiar with his or her local laws.

Summary

It is critical that pediatricians and other health care professionals become knowledgeable about HIV, laws regarding informed consent for HIV testing and treat-

ment, and issues of confidentiality and parental disclosure. Here are some of the general questions the health care professional should ask when presented with the following patient:

If an adolescent presents for HIV testing

- What is your state HIV or HIV-related consent laws for HIV testing?
- Is there a minimal age requirement?
- What is the legal status of the minor?
- Can the minor give informed consent?
- What is your state parental disclosure law for HIV?

If an adolescent presents for HIV treatment

- What is your state HIV or HIV-related consent laws for HIV treatment?
- Is there a minimal age requirement?
- What is the legal status of the minor?
- Can the minor give informed consent?
- Was the minor able to give consent to HIV testing under the law?
- What is your state parental disclosure law for HIV?

Conclusions

This review underscores the need for pediatricians and other health care professionals to become knowledgeable about HIV, laws regarding informed consent for HIV testing and treatment, and issues of confidentiality and parental disclosure. This review also highlights the complexity associated with the lack of homogeneity in state laws concerning consent for HIV testing and treatment as well as the lack of clarity that is problematic for clinical situations. However, there are many provisions in existing laws that allow the adolescents to be given the care needed based on the clinical assessment of the clinician. Thus, awareness of these laws is a central and essential component to stemming the spread of the HIV/AIDS epidemic, particularly given the rapid spread of HIV infection among adolescents.

An important step toward halting the spread of this epidemic is by making the infected person aware of their HIV status through testing. However, a large proportion of adolescents are not tested for HIV. This is especially the case for those at highest risk for HIV.[9] The impact is that those who are unknowingly infected will continue to transmit the HIV infection to sexual partners and offspring as well as to needle-sharing partners, and thus, adding to the HIV/AIDS crisis.[9] Furthermore, there are missed opportunities for early treatment with antiretroviral therapies and improvement in the quality of life.[4] Although there is limited information on the characteristics of youths who do not obtain testing,[4,9] several identified barriers to testing may be involved including confidentiality issues,[4,9,29] ease of testing,[4] limited access to testing and care,[4] physician or health care provider biases,[4,29] and patient denial or ignorance of risk.[29]

Overall, it is imperative that pediatricians and other health care professionals be well informed about issues of HIV infection, informed consent for testing and treatment, and matters regarding confidentiality and parental notification in order to ensure the health of minors and to stem the spread of the HIV/AIDS epidemic. Furthermore, there is a need for clinical research regarding whether a uniform national policy permitting minors to consent to testing and treatment without mandatory parental disclosure will improve rates of testing in minors, patient outcomes, and decrease rates of HIV/AIDS.

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