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Annotation: Adolescent HIV Testing—Who Says Who Signs?

Half of the 30 million people in the world with human immunodeficiency virus (HIV) became infected before the age of 25 years.¹ Only a small portion are aware of their HIV status. HIV testing has become a controversial component of the spectrum of services. The question of whom to test, how to test, where to test, and who says to test are paramount. Most experts agree that counseling and HIV education should be available to all adolescents,² but HIV testing has engendered several controversies.³ Policies vary enormously, from mandatory testing requirements for applicants to the Job Corps or the military, to programs for street youth that recommend not testing at all unless comprehensive services are in place for those whose tests are positive.

The majority of organizations concerned with adolescent health and well-being recommend making HIV testing available given the adolescents' consent in the context of a continuum of counseling (before, during, and after HIV testing), together with assurance of comprehensive care for those whose tests are positive.⁴ The possibility of improved outcomes for HIV-infected people of all ages demands appropriate and adequate training and availability of health care providers, a requirement that is not yet in place in America.⁵

Every state has a law that permits minors to consent to the diagnosis and treatment of sexually transmitted diseases, but not all states classify HIV infection as a sexually transmitted disease. At least 13 states have statutes that explicitly allow minors to consent to HIV testing.⁶ Seven have specific laws authorizing minors to consent to treatment as well. Adult status is conferred at different ages by different laws. However, all persons over the age of 18 are adult.

The study by Meehan et al. in this issue of the Journal is instructive in several regards.⁷ The authors took advantage of a fortuitous event in Connecticut. During the study period, the law changed

from requiring consent by parents (October 1991 through September 1992) to consent by adolescents alone (October 1992 through September 1993). The overall number of adolescents seeking HIV testing increased by 44%. There was a preponderance of high-risk youth among the increased proportion of youth seeking testing, with no change in the rate among low-risk adolescents.

The controversy centers around the implications, for the behavior and health of adolescents, of having a negative or positive HIV test. Most would agree that knowing one's serostatus is important, because early intervention and treatment can prolong health and reduce transmission to others. On the other hand, if treatment is not available or if knowledge of serostatus does not have the intended result, then having the information is of little benefit to the individual or the society as a whole. Herein lies the controversy regarding adolescents. Most experts in the field agree that HIV testing should be performed as part of a program that offers counseling. Since there is a dearth of age-specific, comprehensive programs for youth in general and HIV-infected youth in particular, there is considerable reluctance to push for more testing without appropriate backup and services for those who test HIV positive.

The availability of home testing kits approved by the Food and Drug Administration (but which have now been withdrawn by the manufacturers) has brought this dilemma to the forefront.⁸ Although these tests are supposed to be available only to adults, the notions of home testing and consumer empowerment have been helpful to adolescents under some circumstances: namely, when adolescents have the support and resources to handle the consequences of the test results.

Pregnancy tests for home use are currently used by many minors, but for most young people, the implications of a positive test are even more calamitous for an HIV test than for a pregnancy test. The

circumstances that resulted in HIV infection—namely, unprotected intercourse or intravenous drug use—are in themselves touchy ones for adolescents to disclose to family members, school authorities, or other adults. The consequences of disclosure can be drastic—expulsion from home, school, training program or job—hence, the circumstances of HIV testing are critically important.⁹

Pregnant teenagers highlight the special issues inherent in HIV testing. The results of the "076 protocol," which demonstrated that maternal-to-fetal HIV transmission could be remarkably reduced, has led to new stipulations in the Ryan White CARE Act enacted by Congress in 1990 and amended in 1996. These laws require states to increase the percentage of women who are tested prenatally; they set specific target rates for specific dates, after which testing of newborns with results disclosed to mothers will be mandatory. This new policy heightens the awareness of the special issues involved in testing minors. Current Public Health Service guidelines recommend the routine offer of voluntary testing as part of counseling for pregnant women, many of whom are minors.¹⁰ Twenty-nine percent of women ages 15 through 19 in the United States had been tested for HIV by 1990.¹¹ The impact of the new requirements of the Ryan White Act on young women and their partners and offspring will be particularly important to document and follow.

Although this annotation focuses on consent for testing, a related article in this issue deals with parental involvement in minors' access to services, namely abortions.¹² There are differences in the way the country has dealt with access to diagnostic vs treatment services. Generally speaking, minors' access to services and treatments is more limited than their access to diagnostic tests. Emergency care

Editor's Note. See related article by Meehan et al. (p 1338) in this issue.

can be given without parental involvement (with "emergency" usually defined as a situation in which the health of the minor would be seriously compromised by delaying to obtain consent or in which the minor might flee from care).

Guidelines for consent for adolescents participating in health research have recently been published.¹³ Considering the legal, ethical, and developmental issues and the research setting, the guidelines provide a framework for facilitating adolescent participation in appropriate research studies. In relation to HIV and adolescents, HIV testing has been proposed as part of some research protocols. Minors might participate under their own consent when certain criteria regarding the degree of risk, the nature of the benefit to be gained, and other factors are considered.

In summary, it might be said that adolescents can and should be responsible for decisions related to their own health and that minors, in many circumstances, can and should be able to give consent for confidential services, including sexually transmitted disease and HIV tests. This should not be done in a vacuum. For this

right and responsibility to work, knowledgeable, helpful, supportive adults are required. □

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Annotation: The Accurate Measurement of Gestational Age—A Critical Step Toward Improving Fetal Death Reporting and Perinatal Health

In this issue of the Journal, Gaudino and colleagues offer a method to identify and correct "problem" gestational age and birthweight values on fetal death records.¹ They aim to encourage states to use quality assurance procedures to improve vital records data. While investigations into methods to improve data quality generate considerably less excitement than many other research topics in our field, the importance of this area should not be overlooked. There are several critical reasons why improving the quality of fetal death records should be given a high priority at this time. Moreover, improving the accurate measurement of gestational age is fundamental to this effort, in part because most states include gestational age in their criteria for reporting fetal deaths.²

Although the annual number of fetal deaths in the United States exceeds the number of neonatal deaths,³ much of the published research on the risk factors for poor pregnancy outcomes is based on live

births. Fetal deaths may be excluded from many analyses because of concerns about the poor quality of fetal death data. Nevertheless, our failure to focus on the entire continuum from conception through infancy limits our understanding of the full impact of perinatal risk factors and interventions. As our efforts to reduce infant mortality in the United States are increasingly directed toward the prevention of very-low-birthweight and preterm deliveries, where the distinction between a stillborn delivery (fetal death) and a live-born infant who immediately expires may be open to interpretation, there is a growing need for data of good quality on all deliveries.

Accurate assessments of temporal changes in perinatal health status, as well as evaluations of related interventions and policy initiatives, are enhanced by the availability of good-quality fetal death data. It has been suggested that trends toward the increased reporting of deliveries of less than 500 g as live births, rather

than fetal deaths, or not reporting at all, may partially underlie the apparent lack of improvement in low-birthweight rates in parts of the United States.⁴ The existing variation among states, both in requirements for fetal death reporting and in the quality of fetal death data, precludes an unambiguous interpretation of these trends and therefore hinders valid appraisals of national efforts to reduce low-birthweight and preterm birthrates.

Fetal death data are also needed to interpret geographic comparisons of low birthweight and infant mortality rates, which may be biased by variant obstetric practices, in addition to differences in vital event definitions and reporting characteristics. The increasingly early delivery of high-risk pregnancies raises the frequency of preterm live births and transfers the risk of mortality from the fetal to the neonatal

Editor's Note. See related article by Gaudino et al. (p 1323) in this issue.