HIV Prevention in Adolescents: Removing Obstacles and Protecting Human Rights

A disturbingly high proportion of new HIV infections occur in adolescents and young adults, and far too many young people are dying of AIDS-related illnesses. As noted by Shah et al. [1] in their important study of obstacles to HIV prevention research in adolescents, globally one-third of new HIV infections are in the 15- to 24-year age group. HIV prevention for young people is therefore an essential public health imperative. Successful HIV prevention efforts must include research, outreach and education, HIV testing and counseling, and access to preexposure prophylaxis (PrEP) as well as HIV treatment.

Obstacles exist to effective HIV prevention for all age groups. For adolescent minors, younger than 18 years, the impediments may include legal constraints. The most common is a requirement of parental consent, which may apply to both clinical care and research, with some important exceptions. Ensuring that young people are able to benefit fully from HIV prevention efforts has important human rights implications.

Parental Consent and HIV Prevention Research

The study by Shah et al. [1] explored a wide range of barriers to HIV-prevention research in two populations aged 14–17 years: female adolescents in Kwazulu-Natal, South Africa, and male and female adolescents seeking services at a hospital-based sexually transmitted infection clinic in Denver, Colorado. The study specifically inquired about the extent to which a parental consent requirement would affect adolescents’ willingness to participate in a hypothetical HIV prevention study and how a parental consent requirement ranked in importance compared to numerous other potential barriers. Three separate aspects of the adolescent subjects’ concerns about parental consent were explored: the fact that parents must consent; the possibility of parents thinking they were sexually active or using drugs; and fears that parents might be upset.

The study by Shah et al. [1] confirmed that a combination of factors related to parental consent play a substantial role in inclusion of adolescent minors in HIV-prevention research. More than two-thirds of participants thought parents having to consent was an important barrier. Almost one half said they would be “much more likely” or “a little more likely” to participate in an HIV-prevention study if parental permission was not required. Also, collectively the three barriers related to parental consent were the most important in comparison to any of the other barriers.

The study authors recommend “legal reform and scholarship” to expand the use of parental permission waivers in HIV-prevention research in “innovative ethically and legally appropriate ways” [1]. They also urge that flexibility be maintained to allow for involvement of parents or other trusted adults for vulnerable adolescents. These goals are laudable ones for furthering HIV prevention for this age group; achieving them will require a broad understanding of how parental consent requirements affect not only research but also other HIV-prevention measures.

Context Matters

The requirements for parental permission for research with children, including HIV-prevention research with adolescents, do not exist in isolation. Parental consent is also an issue for HIV testing and counseling, PrEP, and HIV treatment; access to all these is essential for adolescents’ own protection and to protect public health. Also, concerns about parental consent are closely intertwined with concerns about confidentiality. To understand this broader context, two key factors are important: the concerns and perspectives of adolescents, parents, health-care providers, and researchers; and the laws, policies, and ethical guidelines that exist in the United States and globally.

Consent requirements are not separable from confidentiality concerns [2]. Particularly when risky behaviors such as sexual activity or substance use are involved, as in the case of HIV, requiring parental consent also leads to the potential for disclosure of sensitive behavioral information. Findings from decades of research have documented that privacy concerns influence where and when adolescents seek care and how open they are with their health-care providers [3]. Parents and health-care providers often recognize the importance of enabling adolescents to access care, with confidentiality protection when that is essential [3]. Adult support is also important, and many adolescents voluntarily involve their parents, especially with the facilitation that health-care providers can and do offer [3].

Against this backdrop, a plethora of laws, policies, and ethical guidelines govern consent and confidentiality in
clinical care and research. The laws vary among countries; in the United States, the laws also vary among states [4–6]. In the HIV realm, key questions pertain to when adolescent minors may participate in research or receive HIV testing and counseling, PrEP, and HIV treatment with antiretrovirals and other therapies based on their own consent and when they can expect the information about their participation and receipt of care to remain confidential [6–9]. There is also wide variation in how laws are implemented: The existence of a law or guideline is not a guarantee of access; adolescent-specific guidance is essential [10,11].

Adolescents and Laws Governing Access to HIV Care and Research

The laws governing adolescent minors’ access to HIV testing, clinical care, and research vary significantly among US states and from one country to another [4,6]. Sometimes HIV is subsumed under laws governing other sexually transmitted infections; sometimes specific provisions address HIV testing and/or treatment [7]. In some circumstances, the laws are silent. Adolescent minors may be allowed to consent to HIV testing, but not treatment, or they may be able to receive testing and treatment, but not PrEP, based on their own consent, although the laws related to PrEP are evolving [7,8,12,13]. At least one noteworthy example of a variation in laws governing consent for clinical care for adolescent minors is found in the two countries where Shah et al. conducted their study: South Africa and the United States [1]. In South Africa, consent for medical care for adolescent minors is found in they have the maturity

A comprehensive HIV-prevention measures that ensure adolescents’ participation in research and their access to testing and counseling, PrEP, and HIV treatment, these countries fail to honor and uphold their obligations to protect the human rights of young people, including those at the highest risk for and living with HIV. Shah et al. recognized the essential role of research in comprehensive efforts to prevent HIV in adolescents [1]. Their study is an important exploration of the ways that parental consent, as well as other obstacles, might hinder full inclusion of adolescents in research. Their findings could also illuminate efforts to protect the human rights of adolescents in the broader HIV-prevention context.

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References


HIV Prevention and the Human Rights of Adolescents

The human rights of children and adolescents are set forth in a myriad of international declarations, conventions, and treaties. They are also elaborated in numerous guidance documents detailing global health principles, for HIV as well as other health conditions. For example, Article 25 of the Universal Declaration of Human Rights articulates a right to health, well-being, and medical care [17]. Article 24 of the U.N. Convention on the Rights of the Child guarantees a right to the “highest attainable standard of health, treatment of illness, and rehabilitation of health” [18]. The World Health Organization has issued guidance on HIV and adolescents that incorporates these human rights principles [19]. To the extent that countries fail to put in place—or fail to implement—laws, policies, and ethical guidelines for comprehensive HIV-prevention measures that ensure adolescents’ participation in research and their access to testing and counseling, PrEP, and HIV treatment, these countries fail to honor and uphold their obligations to protect the human rights of young