

# Ethical and Psychosocial Considerations in Informing HIV-Exposed Uninfected Children That They Were Exposed to HIV and Antiretroviral Medications In Utero

We build on what is known about the potential long-term health effects of perinatal antiretroviral medication exposure to examine ethical and psychosocial issues associated with disclosure by applying lessons from other health conditions, theories of child and adolescent development and rights, and the relevant literature and legal contexts.

We present 2 cases to highlight potential issues; apply a bioethical framework that includes principles of autonomy, beneficence, nonmaleficence, and justice; and explore other factors, including the current uncertainty about these exposures' possible long-term health risks.

This ethical framework can help clinicians and researchers consider and balance relevant concerns in deciding whether to inform offspring of HIV and related exposures. (*Am J Public Health*. 2016;106:1390–1396. doi:10.2105/AJPH.2016.303257)

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**T**he scale-up of antiretroviral (ARV) treatment and prevention of mother-to-child HIV transmission services promise to continue to reduce new HIV infections in children. Yet, the millions of children for whom HIV infection is prevented will nonetheless be exposed to HIV and ARV medications in utero and often postnatally during breastfeeding. More than 1 million HIV-exposed but perinatally uninfected (HEU) infants are born yearly.<sup>1</sup>

In situations in which ARVs have been used to prevent mother-to-child HIV transmission for more than 2 decades,<sup>2</sup> HEU children are becoming young adults. Data on the impact of perinatal HIV and ARV medication exposures are generally reassuring regarding congenital anomalies,<sup>3</sup> birth outcomes,<sup>4,5</sup> and early postnatal growth.<sup>6</sup> Yet studies have identified associations between ARV exposures and bone,<sup>7</sup> cardiovascular,<sup>8,9</sup> metabolic,<sup>10</sup> and mental health problems.<sup>11,12</sup> Furthermore, although rates of cancer among perinatal ARV-exposed uninfected children do not appear elevated, ARVs may increase risks of cancer in adulthood.<sup>13</sup>

These findings' long-term clinical importance is presently unclear. Although current

evidence suggests that ARV treatment's benefits far outweigh any harms, other perinatal exposures can have long-term health consequences.<sup>14–16</sup> Diethylstilbestrol (DES), for example, was prescribed for pregnant women for nausea for more than 30 years before severe long-term harms to mothers and offspring were demonstrated.<sup>14</sup> Both the children and grandchildren of women DES users may have slightly increased risks of cancer<sup>17</sup> and birth defects.<sup>18,19</sup> But associations are determined by small numbers of events, and ongoing investigators of these grandchildren are seeking to clarify these possible links.

Other perinatal exposures (e.g., alcohol, influenza virus) have also had long-term health consequences that may be unseen for years.<sup>20</sup> Because of the uncertainty about perinatal ARV exposure, the Department of Health and Human Services recommends that HEU children be followed into adulthood

because of the potential carcinogenicity from nucleoside analog ARVs.<sup>21</sup> Hence, clinicians have begun grappling with whether HEU youths have the right and need to know about their HIV and ARV medication perinatal exposures. Disclosure to HEU youths could increase their awareness of potential health consequences and let them monitor themselves and seek relevant health care.

Yet disclosure requires revealing mothers' HIV infection. Mothers may not want to disclose their infection to their child for many reasons and often have legal rights not to do so.<sup>22</sup> Related challenges emerged earlier in the pediatric HIV epidemic, pitting HIV-infected mothers' right to privacy against their HIV-infected offspring's right to know their own diagnosis.<sup>18</sup> This tension became exacerbated with the availability of ARV treatment and the aging of HIV-infected youths into adolescence—a period of increased autonomy,

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treatment decision-making rights, and sexual behavior.

Disclosure to HEU children poses different, but related questions: the “right of the child” argument may have less urgency than it does for children with transmissible and potentially fatal infections; however, questions remain concerning mothers’ rights to privacy, particularly because of the stigma of HIV, versus children’s rights to health information. Examining previous ethical tensions related to pediatric HIV disclosure provides a framework for exploring HEU children’s rights and suggests 3 key questions: (1) What factors determine whether children should be told specific health information? (2) When do children’s rights to information trump mothers’ rights to privacy? and (3) How should such disclosures occur?

We examine ethical and psychosocial issues associated with disclosing this information to HEU offspring. We apply lessons from pediatric chronic disorders, including HIV and other perinatal exposures, theories of child and adolescent development and rights, and the literature on mothers’ rights to privacy and decision-making about their children’s care.

## BACKGROUND

US legislation does not directly address disclosure to HEU offspring but does provide a framework for approaching such questions. Generally, laws tend to privilege beneficial health outcomes (e.g., permitting adolescent consent without parental involvement for treating sexually transmitted infections). Laws also honor (and give precedence to) rights to medical privacy and confidentiality, except when

a third party’s health is at risk (e.g., the Tarasoff case).<sup>23</sup> State medical privacy laws also vary, sometimes requiring providers to give patients access sooner than the 30-day period the Health Insurance Portability and Accountability Act (HIPAA; Pub. L. 104–191, 110 Stat. 1936, August 21, 1996) allows.<sup>24</sup> State laws and codes of medical ethics may also address when disclosure of an individual’s health information for another person’s benefit is permissible.<sup>25</sup> For instance, more than 30 states have mandated that HIV-infected persons disclose their HIV status to sexual partners, supporting mandated disclosure of otherwise private information if imminent harm exists to a third party. Such laws vary and have been criticized for ignoring complex ethical issues (e.g., potential for violence, condom use).<sup>26</sup> Current data do not demonstrate that perinatal HIV and ARV medication exposure causes imminent harm as exposing sexual partners to HIV does.

Because of the absence of explicit laws about disclosures of perinatal exposures, insights from other medical domains—for example, testing for breast and ovarian cancer (BRCA) mutations—prove helpful. As with HIV/AIDS exposure, many mothers with BRCA struggle with whether and at what age to tell offspring who may inherit the mutation. Individuals with BRCA mutations have about a 50% chance of developing the disease. A daughter’s knowledge of future risk may cause anxiety but also encourage appropriate monitoring. Mothers with BRCA often view disclosure to adult offspring as beneficial but hesitate with younger children, who may not understand or cope effectively.

When sharing parents’ genetic test results with children, providing information, checking children’s understanding, and

encouraging ongoing dialogue and support are also important.<sup>27</sup> With BRCA, adolescents do not necessarily need to be told that they may have (and can be tested for) a mutation that increases their cancer risk. Because breast cancer generally does not appear in adolescence, adolescents will not need to take any immediate preventive action, and the mother and her offspring may feel undue anxiety. Thus, although adolescents have rights to information, clinicians generally determine that the potential risks of disclosure outweigh the benefits. Many mothers do, however, tell adult offspring, who may obtain genetic testing, monitor risks, and make appropriate reproductive and prevention decisions.

Some prescribed medications, if taken during pregnancy, can harm the fetus and are thus contraindicated for pregnant women: for example, lithium for bipolar disorder<sup>28</sup> and isotretinoin (Accutane) for acne.<sup>29</sup> Treatment can be readily postponed during pregnancy for acne but frequently not for bipolar disorder. Untreated bipolar disorder can harm the mother’s and thus the fetus’s well-being.<sup>15</sup> Alternative psychiatric medications may also pose risks. Providers routinely inform pregnant women about such risks and help them in decision-making.<sup>30</sup> Yet disclosures to offspring of perinatal psychiatric medication exposure have received limited scholarly attention.<sup>31</sup>

Somewhat parallel issues have emerged with assisted reproductive technologies that involve the rights of children born through donor sperm and eggs to know that they are not genetically related to their caregivers or parents and to learn the identity of, or other medical information about, the donors. Parents may

hesitate to tell a child that he or she was born using such technologies, fearing negative reactions and potential stigma. Professional guidance strongly encourages such disclosures.<sup>32</sup> Disclosures of gamete donation during childhood or adolescence, rather than adulthood, may also have medical and psychological benefits.<sup>33</sup> Offspring who are not told how they originated cannot access their biological parents’ health information and learn of any potential hereditary risks.<sup>17</sup>

Three broad considerations may shape disclosure decisions regarding HIV and ARV medication exposure to these offspring: (1) the medical benefits from disclosure, which depend on the nature of the exposure and the latest medical understanding of whether exposure information has clinical or social utility, (2) the child’s age and maturity (e.g., whether the child is a minor and will understand), and (3) who the adult decision-maker is (the mother vs another caregiver). A mother may decline to share the information with her child, or she may be unavailable owing to her death or other circumstances, creating the dilemma of whether the provider or another caregiver should inform the offspring. These considerations emerge and manifest themselves differently in varying clinical situations.

To examine these issues, we present 2 cases while drawing on a bioethical framework (Table 1) and focusing on 4 key ethical principles: autonomy (respect for persons), beneficence (maximizing the welfare of persons), nonmaleficence (avoiding harm), and justice (advancing social and distributive fairness). These 2 cases raise critical issues and complexities and illustrate how the presence, relevance, and importance of each of these principles can differ in specific

situations. We have described and analyzed each case, reflecting on the relevant ethical principles. These principles can provide useful rubrics for clarifying and organizing many of the underlying issues, even though larger medical, social, psychological, and ethical complexities and uncertainties persist. This framework can thus highlight key issues, even if it does not resolve them.

## CASE 1

Martina, an HIV-positive woman, aged 40 years, is the mother of Juan, an uninfected boy aged 11 years, who, per standard treatment guidelines, was exposed to zidovudine in utero and during the first 6 weeks of life. A single mother, Martina likely contracted HIV from Juan's father, who had used injectable drugs. The family lives in a small, socially and politically conservative Texas community with widespread stigma about HIV and injectable drug use. Texas had relatively high rates of maternal and pediatric HIV cases early in the epidemic, which particularly affected Latinos. Martina has watched friends experience discrimination, including hate crimes, after disclosing their status. Martina has not told any of her family members, including Juan, about her HIV status. Juan has had routine annual check-ups at the outpatient clinic that has followed him since birth.

After Juan's 11th birthday, Martina was transferred to a larger Texas city for work. She found a new clinician for Juan, who received his medical records from the previous physician. The new clinician asked Martina if Juan knew about her HIV status and, if not, whether she planned to tell him. Martina does not want Juan

to know, fearing that it will upset him, that he will ask questions about how she became infected, and that he may disclose the information to others.

The 4 ethical principles provide a useful framework for considering this case.

## Autonomy

Martina and Juan each have certain rights of autonomy. Martina has rights to privacy concerning her health information and to raise her son as she feels is appropriate, provided she does not harm him.<sup>34,35</sup> Yet Juan also has rights to autonomy that might include the right to know about his HIV and ARV medication exposure. Autonomy dictates that individuals, including children, have some degree of voluntariness in their decision-making. Yet, minors' capacity to understand relevant issues may be limited. Thus, caregivers are typically given ultimate authority for medical decision-making until their children reach adulthood (usually at age 18 years).

Before age 18 years, children do not necessarily provide full informed consent for care but typically provide assent ("affirmative agreement").<sup>36</sup> Minors should receive information appropriate for their development stage.<sup>37</sup> Still, dilemmas emerge concerning the specific content and scope of this information. Clinicians often need to assess minors' capacity to understand the information.<sup>38</sup> Older children and adolescents vary in when they can fully understand and make health care decisions. Emotional and developmental differences between individuals are not always age-based; yet, increasingly, providers recognize the importance of involving adolescents in decision-making.<sup>39</sup>

Moreover, by age 18 years, Juan will have full legal rights to access his records. If he seeks his childhood records and these indicate his prenatal exposures, Martina will be unable to hide this information. This issue may be increasingly relevant as electronic health record use increases, and prenatal data may be included. Martina and the provider will need to consider the impact of withholding information on their relationships with Juan even if they decide that Martina's autonomy is currently more important.

Martina and the provider should consider how best to prepare him so that he is not surprised by the information that the provider may be obligated to disclose if Juan asks for his records or if the information is medically relevant to monitoring or to other choices Juan might make. This situation thus differs from disclosures concerning BRCA or donor sperm use, which would presumably not be in the child's medical record. With BRCA, a mother's provider may be obligated to urge her to disclose the information to her daughters, or the provider can disclose for the mother, but the mother's test will not already be in her child's records.

## Beneficence

Clinicians need to pursue beneficence—maximizing the well-being of both mother and child. Martina may believe that continued secrecy maximizes her psychological well-being, reduces stress, avoids upsetting Juan, and minimizes the risk of discrimination from HIV or other issues (e.g., ethnicity).

Her experiences in a conservative community might make her wary of Juan disclosing the information to others and of the potential resulting stigma or

rejection. Conversely, disclosure might increase support for her and Juan, reduce any confusion Juan might have, and benefit the family psychologically.

## Nonmaleficence

Disclosure to Juan could harm both mother and child because of possible discrimination or psychological distress. But nondisclosure can also cause harm. Nonmaleficence may support a decision to tell Juan about his ARV exposure if Juan senses that his mother is sick or has HIV. Even when caregivers withhold the cause of illness or death, children may learn of a family member's disease by hearing another relative disclose the information, by discovering related documents, or by piecing together various facts (e.g., finding pill bottles or seeing Internet search histories). Offspring may then feel betrayed and angry. Clinicians can ask parents or caregivers whether children have expressed concerns about parental health.

Additionally, if researchers discover that prenatal HIV and ARV medication exposure are harmful, Juan would eventually need to know to be appropriately monitored and ensure his participation in medical decisions. Unfortunately, the long-term risks of HIV and ARV medication exposure remain uncertain. Nonetheless, nonmaleficence suggests that clinicians remain aware of possible risks—particularly because of the history of DES.<sup>14</sup> If evidence grows about ARV exposure's possible dangers, the ethical calculus will shift. Because of current uncertainty, nonmaleficence suggests it is better to err on the side of caution and act as if HIV and ARV medication may cause some harm in a certain, albeit probably relatively small, proportion of exposed individuals. Hence,

TABLE 1—Issues Concerning Disclosures of in Utero ARV Exposures to Offspring

Ethical Principles	Arguments Against Disclosure	Arguments in Favor of Disclosure	Factors Involved and Clinician's Options
Autonomy	Mother's autonomy Right to privacy and confidentiality concerning health information about Herself Her child until age 18 y	Offspring's autonomy Right to know pertinent health information about self Offspring will have right to the information at age 18 y	Clinicians may have to balance rights of mature minors vs rights of parents
Beneficence	HIV and ARV medication information may upset the child	If in utero ARV exposure is found to be physically harmful, awareness, prevention, and treatment may be beneficial Disclosure could potentially reduce child confusion Disclosure may help bond instead of distancing mother and offspring	Need for ongoing research Clinicians can discuss these issues with the mother
Nonmaleficence	Mother may face discrimination Child may face discrimination	Offspring may feel betrayed by mother and clinicians if finds out only later, perhaps inadvertently	Offspring may understand need for privacy and avoid disclosure and thus discrimination
Justice	Patients may face other psychosocial vulnerabilities	Disclosures can help patients and offspring obtain appropriate care and services and address other vulnerabilities If adolescents are sexually active and have children, ARV exposure, if found to be harmful to more than 2 generations, could harm these future children	Clinicians need to proceed carefully

Note. ARV = antiretroviral.

especially if over time evidence of possible toxicity increases, clinicians may conclude that non-disclosure is no longer in the offspring's best interests.

## Justice

Concerns about social and distributive justice may arise because patients (e.g., Martina and Juan) may face multiple stresses associated with previous stigma or discrimination related to ethnicity, race, socioeconomic status, educational attainment, mental health, or substance abuse. Most US children born with HIV are African American or Latino, and thus their families have often experienced years of racism and discrimination, independent of HIV, and have learned to be wary of the medical system.

Providers need to be sensitive to these vulnerabilities and to the fact that most families will be addressing disclosure in the contexts of multiple issues and concerns that

seem more compelling. Moreover, if the information is in Juan's records and he does not know about it, he may, upon adulthood, unsuspectingly share his records with others, inadvertently exposing him to stigma, discrimination, or other problems. Knowledge of what is in his medical records may thus help him to protect himself against these risks. Meeting with parents to address these concerns will be important.

## Resolving Tensions in Ethical Considerations

Overall, these considerations might support a clinician's decision not to compel Juan's mother to disclose the information to him now. Considerations supporting nondisclosure are Martina's right to privacy, concerns about possible discrimination that can exacerbate other stresses, and Martina's right to determine how she raises her son.

Juan is still relatively young; no clear evidence indicates that there are perinatal HIV and ARV medication exposure-related health consequences, and no specific recommended actions exist beyond nonspecific monitoring.

The situation might differ if Juan appeared harmed by the silence: for example, if he suspects his mother is HIV positive and he becomes worried—especially if he asks about the issue or if new research suggests ARV-associated harms. Because of changing developmental needs and the potential for new scientific findings, it would be prudent for the clinician to revisit disclosure decisions with Martina as Juan ages.

## CASE 2

Rebecca, an African American high school student aged 16 years, has received care from the same clinician since birth. Her

mother died of HIV when Rebecca was aged 5 years. Rebecca is uninfected but was exposed to HIV and ARVs in utero. She lives with her father and stepmother, who are both HIV negative. She often asks about her birth mother, including how she died, but her father has been evasive. Rebecca is interested in a career in medicine and has recently read about the potential consequences of perinatal exposure to tobacco and alcohol in a health class. She asks her father about whether she was exposed to anything in utero. He does not want to tell her about her mother's HIV status for fear of revealing family secrets related to how Rebecca's mother became infected. Although somewhat mistrusting of doctors, he mentions this issue to Rebecca's clinician.

This case presents several concerns similar to those in the first case but also several key differences. Rebecca, like Juan, is



a minor, but she is at a different developmental stage and has specifically requested information. As an older adolescent, she may also be or become sexually active, raising additional questions because of possible risks from DES to children and grandchildren of women who took that drug.

### Autonomy

Rebecca, who is older than Juan, seems to have more interest in, and ability to understand, health information. Denying her information because of the belief that she would not understand it is therefore unreasonable and might involve lying or withholding information about both her and her deceased mother's health. Clinicians thus need to respect Rebecca's right to information. If someone aged 16 years asks, clinicians might work with caregivers to address possible disclosure.

Many states also recognize that mature minors (aged 16 or 17 years) have certain rights, such as access to reproductive care. Although parents may fear rejection from their children and discrimination, clinicians could work with the family concerning family relationships and confidentiality.

### Beneficence

Although nondisclosure might benefit Rebecca's father (reducing stress and parent-child tension), disclosure might also benefit Rebecca and help her address questions about her and her mother's health. Moreover, if in the future perinatal HIV and ARV medication exposures are linked to long-term risks, especially if preventive actions are recommended, the benefits of disclosure are clear.

Conversely, if HIV and ARV medication exposure is eventually found definitively not to have long-term risks, disclosure to offspring may provide less benefit. Parents may engage in behaviors and have had diagnoses that do not harm the fetus, and parents often keep such information private; for example, mothers may have had alcohol or substance abuse before becoming pregnant that they keep secret. Clinicians do not ordinarily disclose such information to offspring if mothers do not wish to share it.

### Nonmaleficence

Rebecca's father may have experienced or feared racism and stigma, and he may worry about her having to confront another source of stigma. However, because Rebecca has specifically asked about her health exposures, if she later finds this out (e.g., at age 18 years), she may feel betrayed because she had explicitly requested information.

She may view such withholding differently—as more reprehensible—than if she had never asked. Moreover, if Rebecca is sexually active, there is a possibility, even if not high, that she could have a child. If, as with DES, HIV and ARV medication exposure is found to extend to future generations, then this child, too, may be affected.

### Justice

As in case 1, Rebecca and her father may be confronting multiple social and psychological vulnerabilities, highlighting the need to consider disclosure decisions within the broader contexts of parental, familial, and community-level stressors that may also influence youths' well-being.

Moreover, if ARV exposure is eventually found to be harmful, and if Rebecca is sexually active and gives birth, the exposure can affect others, too. Rebecca may have children after, rather than before, she turns 18 but will then have legal access to her medical records.

### Resolving Tensions in Ethical Considerations

These ethical considerations point more toward disclosing HEU information to Rebecca. She is aged 16 years, is requesting the information, presumably could understand much of it, and has certain rights to it. Secrecy may cause more confusion and distress than disclosure; silence can also cause psychological and physical harms.

Disclosure can offer benefits, such as sensitizing her to the difficulties her father may be confronting. Ideally, clinicians should work closely with him—because of other stresses he may be facing—discuss these issues, and encourage and facilitate disclosure while promoting general communication between Rebecca and her family.

### CONCLUSIONS

An ethical framework can help clinicians systematically articulate, consider, and balance relevant concerns in deciding whether to inform HEU children of exposures. This framework can encourage clinicians to balance several potentially competing psychological and physical harms to the parents and offspring with benefits and possibly less-tangible rights. Parents can often judge best what their children can handle; therefore, clinicians should respect parents' knowledge of their children's

cognitive, emotional, and coping capacity. Still, parents may have difficulty focusing on their child's needs because of fears about mortality, fears of disclosure's harms to parent-child relationships, stigma, and other factors. Clinicians can explore parental beliefs and values and validate concerns. Clinicians should approach these topics carefully, especially because of the sensitivity of these issues in communities that are wary of medical care owing to histories of racism, discrimination, and poor health care access. These discussions and disclosures should not be one-time conversations but ongoing processes.

Other situations may also affect HEU disclosure decisions. For instance, those aged 16 years are unlikely to ask about perinatal exposures, and clinicians generally do not raise the issue. Typically, providers are busy and must triage, focusing on the most pressing health concerns of the moment. Moreover, mothers can articulate their rights to privacy more than children can express their right to information that they may not even know exists. Although children may not articulate their rights, clinicians must always consider them. Clinicians may avoid this potentially difficult topic. Yet, it is important that they address disclosure with parents, if appropriate, particularly if it might be in the child's best interest.

Challenges emerge, too, when young people transfer from pediatric to adult care, usually between ages 21 and 24 years. Pediatric medical records may not get transferred, and adult providers may therefore not know a person is HEU. Problems could emerge if information about exposures is not included in the adult medical record, and ongoing research indicates the

importance of this information—perhaps for undergoing interventions to address newly discovered harms from ARV exposures. If future studies indicate a reasonable possibility that perinatal ARV exposure causes harm, clinicians should, arguably, inform the offspring before the transfer or by age 18 years and potentially earlier so that the offspring can make informed health care decisions.

HEU information may, however, get linked or included in the offspring's medical record, regardless of parents' disclosure preferences. Electronic health record use is increasing, often with online patient access to all medical records. Individuals, at age 18 years, may learn of exposures and feel angry, confused, or distressed.<sup>39</sup> Clinicians could discuss this potential for such scenarios with parents.

These tensions have broader implications because HEU issues provide an important prism through which to explore critical ethical questions concerning offspring's rights to know about other perinatal exposures (e.g., psychiatric medications). The complex issues we have raised highlight the need for research to better understand long-term implications of HEU and to identify how best to share this information in families and as part of offspring's health history as they become adults. Research is needed, too, to examine the psychosocial contexts and implications of possible disclosures and parents' and offspring's preferences under various circumstances.

Infants born early in the HIV epidemic are now in their 30s, and many have offspring of their own. However, to follow multiple generations of exposed individuals and assess potential long-term harms will take

time. Moreover, new HIV medications are continually introduced. Hence, uncertainty will likely persist for decades. Clinicians should therefore proceed with care.

Clinicians will continue to face questions concerning whether and when to disclose prenatal exposures to ARV and other medications to offspring, and long-term health risks remain uncertain. Ethical frameworks can help providers assess and weigh the relevant considerations and guide appropriate practice. **AJPH**

### CONTRIBUTORS

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The New York City Department of Health and Mental Hygiene institutional review board determined this study to be program evaluation. Therefore no human participant protection was required.

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