



Published in final edited form as:
J Clin Ethics. 2008 ; 19(1): 31–42.

Ethical Issues Concerning Disclosures of HIV Diagnoses to Perinatally Infected Children and Adolescents

Robert Klitzman, MD,

Columbia University, New York, New York, r1k2@columbia.edu

Stephanie Marhefka, PhD,

Columbia University

Claude Mellins, PhD, and

Columbia University

Lori Wiener, PhD

The National Institutes of Health

BACKGROUND

Healthcare workers (HCWs) often disagree with caregivers or parents about whether, when, and how to disclose HIV serostatus to perinatally HIV-infected children, yet the critical ethical, moral, and legal issues involved and their interplay have been underexplored. The purpose of this article is to bring attention to this increasingly important issue and the complexities involved, and to provide a framework for considering disclosure-related challenges.

Worldwide, 2.2 million children live with HIV, with 640,000 infected each year.¹ In the U.S., more than 9,000 children live with perinatal HIV.² Early in the epidemic, when HIV-infected children faced very short life expectancies, few providers were concerned about disclosing the diagnosis to children. However, since the advent of antiretrovirals (ARVs) and their use in children, increasing numbers of HIV-infected children are living longer, often into adolescence and young adulthood. Thus, children are reaching a level of cognitive development that allows them to understand their HIV diagnosis and to participate in treatment decisions, which could affect adherence to often complex medication regimens. Furthermore, older children and adolescents are reaching a level of physical and emotional development that can lead to sexual activity and sexual transmission risks. Sexual transmission is of particular concern among adolescents who may have little sexual experience, and thus be less familiar with safer sexual practices. If perinatally infected youth are nonadherent, they could potentially transmit drug-resistant virus. Thus, providers or other legal guardians/caregivers or parents (all of whom we will refer to below as “parents”) of children with perinatally acquired HIV face the difficult tasks of someday telling their child that he or she is HIV infected.

Disclosure of HIV entails telling children that they have a potentially life-threatening, stigmatized, and sexually transmittable illness. Thus, parents and healthcare providers often disagree about the timing and appropriateness of disclosure. The American Academy of Pediatrics (AAP) recommends that all adolescents know their HIV status and that disclosure be considered for school-age children as soon as is developmentally appropriate.³ However, the AAP provided few concrete guidelines to support providers and families in this process (that is, *when* and *how* exactly to tell, how to decide, how to weigh psychosocial effects of disclosure, and whether full disclosure is ever *not* appropriate).

When disagreements occur about whether to disclose — most commonly when a health-care worker (HCW) recommends that a child be told, and the parent refuses — critical ethical issues

surface. Even when parents and HCWs might concur that the time is right to begin discussing HIV with the child, questions can still arise as to how to disclose — for example, what exactly should be said. Clinicians often need help with these issues, and guidelines for both parents and providers can be helpful. There is little clear guidance.

Commonly, parents delay disclosure until children are at least 10 years old, providing some information about the illness beforehand, without using the terms “HIV” or “AIDS.”⁴ One study, for example, reports that 50 percent of staff, caregivers, and patients thought disclosure should occur before age 12.⁵ Prior research has reported that some parents try to protect their children by attributing the need for medical care to other, more benign, or less stigmatized conditions (for example, asthma or cancer). When full disclosure does occur, the psychological impact on the child and family is not clear. In fact, studies results differ dramatically as to whether a higher incidence of psychological and behavioral problems occur among children who have *not* been told about their diagnosis versus children who have been formally told.⁶ Moreover, critical questions emerge of not just how clinicians *are* addressing these issues, but how clinicians *should* proceed in these cases. How should clinicians think about balancing the rights of the child *versus* the mother, especially as children grow older? Do the rights of the child ever trump those of the parent, and if so, when and why? Who should disclose the diagnosis to the child? One study found that the majority of patients thought they were told at the right time and by the right person, if the latter were a family member, rather than a healthcare provider.⁷

The broader implications of nonadherence, sexual transmission of HIV, and sexual transmission of drug-resistant strains of the virus necessitate thorough analysis and understanding of these issues. Consideration of these ethical dilemmas varies with the circumstance of the case, and in particular, as we shall see, may shift over time due to psychological, medical, and social developments. Hence, this article explores these areas by presenting a clinically based case to illustrate these considerations in disclosure decision making, and outline the complex issues involved.

Several recent general approaches and theoretical perspectives may be applicable here. Fins and colleagues have suggested models of “clinical pragmatism,” drawing on the work of John Dewey, in which in any particular clinical ethical dilemma, both principles and the details of the particular case are considered.⁸ Similarly, Dubler has recently suggested approaching ethical conflicts in clinical care using a “mediation model,” in which, briefly, a “mediator facilitates a discussion between and among the parties . . . to identify their goals . . . and to generate . . . options.”⁹ In addition, the American Counseling Association (ACA) has advocated a seven-step ethical decision-making model incorporating the work of several researchers,¹⁰ that suggests, in brief: (a) identifying the problem, (b) referring to and applying the ACA “Code of Ethics,” if relevant, (c) determining the nature and dimensions of the dilemma, (d) generating potential courses of action, (e) considering the potential consequences of all options and determining action, (f) evaluating the selected course of action to see if it presents any new ethical considerations, and (g) implementing the course of action.¹¹ Such approaches have not been applied to these cases, and we have tried to do so below.

A SAMPLE CASE

We present the following case scenario to illustrate many of these dilemmas. This case is drawn from clinical experience that our team has had. The names and other potentially identifying details of the case have been changed to protect the identity of the patient and her mother.

PART I

Maria, a 36-year-old HIV-infected Latino woman, gave birth to an HIV-infected daughter, Amelia. Maria does not want Amelia to know that either of them has HIV. Amelia is now 10 years old. Amelia has been told she takes medications for “a problem in her blood.” Recently, Amelia says she does not like taking the medication, and occasionally misses doses. The clinic staff have raised the issue of whether Amelia should be told about her diagnosis. In the near future, she will be at the age at which girls often become more interested in boys or sexual behavior. Also, her social worker feels that if Amelia knew her diagnosis, she might be more adherent to her medications.

But Maria says that she absolutely does not want her daughter to know. Maria believes Amelia is still too young, and will be emotionally devastated. Maria says that it is *her* responsibility — and only her responsibility — as a mother to “protect” her child and that her daughter is “not ready” to know. Maria says that Amelia is “a good girl” and will not be sexually active until she is married.

The social worker thinks Maria feels very guilty about having transmitted the virus to her daughter. Maria herself became infected through a former boyfriend, who had a history of intravenous-drug use. Still, the staff is concerned and thinks Maria should begin to reconsider.

The staff thus confronted several ethical dilemmas. Does the daughter have a right to know her diagnosis? Does the mother have a right not to disclose the diagnosis to the daughter? Does a mother have a right to the privacy of her own diagnosis, which could be threatened if her daughter learns of her own status? Should the staff ever tell the daughter if the mother does not want them to? If the daughter wants to know more about her condition, what should the staff say? Should she still be told simply that she has “a blood disease”? Are there other approaches the staff can take, and if so, what?

This case is typical of many. Parents often fear that disclosure may distress the child and other family members. Healthcare providers often advocate disclosure, due to the possible psychological and medical benefits for the child, as well as public health concerns (that is, the possibility of transmission to sexual partners).

Legally, there is no clear mandate concerning most of these disclosure dilemmas. Federal and state laws do not appear to address diagnosis disclosure to children explicitly. Many state laws do protect the privacy of information regarding a person’s HIV status, except in very specific circumstances;¹² and these laws may prevent HCWs from informing a child that he or she was perinatally infected with HIV, as such a disclosure would result in violating the confidentiality of the mother’s HIV diagnosis. In at least one state (that is, Georgia) a physician may be warranted in telling a child that he or she was perinatally HIV infected, as the law supports a physician’s disclosure of a mother’s HIV diagnosis to a child, given reasonable belief that the child is at risk of being HIV infected.¹³

Other laws that address the rights of a child versus the rights of a parent are worth noting. Generally, laws assume that parents act in the best interests of the child. The law might thus support a parent’s decision regarding disclosure. But the law recognizes that in certain circumstances, and for various reasons, parents may not act in their child’s best interest. According to the principle of *parens patriae*, protection of the child’s welfare outweighs the parents’ right to refuse medical treatment for the child,¹⁴ though whether parents nonetheless have a right to refuse disclosure to a child is unclear. The *Storar* case set a precedent that a parent cannot deprive a child from life saving treatment.¹⁵ Similarly, Article 10 of the N.Y. State Family Court Act established a legal procedure to protect children from physical, mental, and emotional mistreatment. However, parents often consent to treatment, but to not disclosure

to an HIV-infected child. Whether nondisclosure alone ever constitutes mistreatment is debatable. Other legal precedents have granted adolescents some treatment-related autonomy. Adolescents may petition courts for “emancipated minor” status to be eligible for healthcare coverage, or may qualify for “mature minor” status that allows older children who understand the associated risks and benefits to initiate certain treatments without parental consent when parental consent may be difficult to obtain.¹⁶ Yet the case of *McChandless v. State* suggested that physicians should not treat a minor without parental consent when the parents are available within one week, during which time treatment delay would not alter the outcome.¹⁷ In all states, an adolescent infected with a sexually transmitted disease (STD) such as syphilis can receive treatment without parental notification, but other STDs differ from HIV, since in some states decisions about parental notification for STD services is at physicians’ discretion.¹⁸ Yet clearly these precedents refer to treatment, not disclosure.

When children are in foster care, only some foster care parents — especially those who have a medical foster home — have legal rights concerning the child’s healthcare. Typically, foster care agencies assume responsibility for the child’s healthcare, and often require consent from biological parents (or the court) before children receive specialized care. Yet how this responsibility and consent apply to disclosure, and how healthcare teams can best address disclosure to children in foster care, is not clear. The AAP states that test results “should be provided by the child’s physician to foster parents, biological parents (if possible), foster care agency and the child (if old enough to comprehend and if disclosure is appropriate to the developmental level of the child).” But this organization does not say when or how foster parents should disclose when the child inquires before being old enough to understand the diagnosis,¹⁹ or when the child is old enough.

In short, in facing dilemmas concerning disclosures to children, given the absence of other legal guidance, HCWs must make difficult ethical decisions.

As depicted in table 1, numerous sets of ethical issues arise both for and against disclosure and need to be considered and weighed — related broadly to principles of autonomy, beneficence, nonmaleficence, and justice. For each of these principles, reasons exist both pro and con. Hence, the specifics of each case play important roles in balancing these issues. These broad categories of concerns overlap, but we use them here to structure and clarify the discussion.

The principle of *autonomy* might dictate that Amelia has a *right* to know her diagnosis. Yet ethically, minors are capable of giving assent, but not consent,²⁰ and parents have certain rights and responsibilities over their children’s care. Reasons to disclose include the notion that a child has a right to know what is occurring in his or her own body, yet Maria, as a mother, might be said to have autonomy as a parent, with rights to challenge healthcare providers’ suggestions. Maria has the responsibility to make decisions about what is in Amelia’s best interest, and thus has the right not to disclose the diagnosis to her daughter if no imminent danger exists. Moreover, arguably, Maria has the right potentially to withdraw Amelia from care (if to do so is not imminently life threatening to Amelia).

The principle of beneficence arises here, since disclosure could increase the child’s sense of autonomy, empowering the child, and facilitating his or her ability to care for him or herself. Knowledge of his or her status could help a child feel more control over certain issues concerning his or her self. Potentially, children who are aware of their status will also not be as angry or resentful about having been kept in ignorance as those who learn only at a later point in their lives.

Yet the ideal of nonmaleficence might suggest that children have a right to be protected from harsh and painful information that is otherwise not necessary, and hence should not be told of

their status. Since the infection did not result from the child's behavior, the child should be protected from the psychological and social burdens of this disease, if possible.

Principles of beneficence and nonmaleficence may be relevant, too, based on medical implications of disclosure decisions. Disclosure may²¹ or may not²² improve children's medication adherence. This difference in findings may be due to various factors, for example, caregiver stress, cognitive functioning,²³ or age of the child.²⁴ Among other chronic conditions (for example, diabetes and asthma), nonadherence increases as children age.²⁵ If medication needs to be taken in public, stigma can hamper adherence.²⁶ Nonadherence may result, too, from parents giving adolescents "too much" responsibility for taking medications, after disclosure. Adolescents may also have difficulty considering the long-term consequences of nonadherence, or may not want to take their medication because it reminds them that they are "not normal," or it might result in unintended disclosure to peers.

Psychologically, too, disclosure can be beneficial and reduce harm. HIV-infected youth who have not been told of their infection may encounter anxiety and related emotional and behavioral problems, sensing that "something is wrong." Disclosure could thus alleviate some anxiety, and facilitate addressing these worries, since fears of the utterly unknown can be greater than those of a known disease. Disclosure may be helpful, too, by facilitating psychotherapy that can address HIV-related mental health issues, since HIV can then be discussed more directly and openly, rather than hidden. Knowledge of their HIV infection may enable adolescents to cope better with the disease and possible fears of death from HIV. Children unaware of their chronic health condition may experience more anxiety.²⁷

Yet disclosure can potentially cause psychological harm, as children may not be equipped to handle the implications of disclosure. *Modified labeling theory* provides a means to understanding some of the psychosocial consequences that might result from disclosure to children: prior to learning of their HIV status, children may have internalized societal conceptions of the meaning of being HIV infected (that is, as associated with risky sex or drug injection).²⁸ Thus, when children learn they are HIV infected, they may need to integrate their previous identity (of being HIV negative) with a new one (of being HIV positive). As they cope with the news of how they became infected, they may have to reconceptualize their mother's and/or father's identity as well. Modified labeling theory suggests that negative labels lead to negative outcomes for the person labeled. When children expect that they will receive negative labels or stigma for being HIV positive, they may respond in several ways, including *secrecy*, which is likely to be encouraged by some care-givers to avoid stigmatization. Such children may try to avoid any indication that they are different from their peers. HIV-infected children may *withdraw* or keep a comfortable distance from others who are known to be infected. Infected children may choose to spend their free time only with their family, who may actually encourage such isolation. Or, some HIV-infected children may affiliate with each other through treatment groups, but avoid being close to other children. Yet secrecy and withdrawal can lead to isolation, in turn fostering poor self-esteem and mental health problems, including depression. Alternatively, some children may want to divulge their diagnosis within their social networks to educate others or gain acceptance. This may result in increased support or, conversely, ostracization.²⁹ Disclosure might further marginalize a child already marginalized due to race, socioeconomic status, or HIV-related disabilities, or promote a false sense of friendships and social support.

Cognitively, children may lack the capacity to understand HIV and its implications, in which case disclosure may cause harm. Many children younger than 10 have less fully developed abilities to understand abstract concepts of having a chronic illness, especially if they do not feel ill.³⁰

Parents face additional ethical concerns as well. As mentioned earlier, the principle of autonomy would indicate that parents or legal guardians have the right to decide when to disclose to a child, because they may know best when exactly a child is prepared. They will also have to deal with the consequences. But to give caregivers unequivocal authority over disclosure might not always be best, since caregivers might not know or be able to do what is best for their child. Their fears that their child will get angry at them, or that parental sexual or drug use risk behaviors will be disclosed could interfere with their objectivity in considering their child's best interests. HIV-infected parents may also have cognitive or mental health problems that impair their judgment.

Medically, the potential benefits and harms of disclosure on maternal health behaviors have been underexplored. After disclosure, a parent may decrease his or her sense of responsibility for medical monitoring of the child. Yet divulgence of a child's HIV-positive status may also increase tensions due to revelations of prior parental secrets. Psychologically, disclosure to a child may benefit the parent, reducing the burden of keeping the secret, and facilitate support and caregiving. Disclosure may also enhance communication and connectedness between the parent and child, since previously the parent withheld information from the child and may have devoted energy to maintaining secrecy. However, following disclosure, if the child divulges the information to others, stigma can increase for the parent and family, adding stress, and possibly fueling maternal guilt, self-hatred, and low self-esteem. Parents may become overwhelmed or burdened by the child's consequent distress. Disclosure could also lead to subsequent divulgence of additional family secrets that parents would prefer remain hidden (for example, concerning a parent's drug use or sexual behavior).

A moral perspective might argue that the child would only need to know his or her status if he or she is sexually active, and because the child should be abstinent anyway, there is no reason to tell.

Given all of the above considerations and fears that Maria could remove Amelia from their medical care, the staff decided that if Maria did not want Amelia to know, they should not disclose at this time. Rather, they decided to delay disclosure, while working with Maria to determine the best time to move forward with the disclosure process. The staff also decided that if Amelia asked, they would refrain from answering, and instead discuss a plan with Maria, since they felt they should never lie about the diagnosis if Amelia inquired about it. Amelia did not ask for additional information about her "blood disease."

PART II

Amelia is now 13 years old. She says that many girls she knows have boyfriends, but she denies that she is dating or romantically involved.

The staff again become concerned, and speak with Maria about telling Amelia, but Maria still refuses to disclose. Maria doesn't want to upset her daughter whom, she feels, seems very well-adjusted. She had spoken to her priest who said that she has a right not to tell Amelia. The staff decide to continue to accede to the mother's wishes.

Six months later, Amelia tells her doctor that she has a boyfriend, but denies having sex. Additional questions now arise as to whether the staff should tell Amelia at this point. Does a 13 year old have a greater right to know than a 10 year old? The staff wrestles with whether Amelia is sexually involved or likely to be in the imminent future.

When a child becomes sexually active, the presence of a third party — the sexual partner— introduces additional complexity into disclosure decisions. Here, the well-being of a third party — the daughter's sexual partner, if one exists — is potentially at stake. The possible harm

caused by nondisclosure could now involve the transmission of HIV to the potential sexual partner, since if the adolescent is aware of being HIV infected, he or she may be more likely to engage in safer sex (that is, using condoms). Although safer sex is by no means guaranteed following disclosure, an adolescent who is unaware of his or her HIV infection lacks this critical information, which can potentially help motivate prevention behaviors. Maria may have the right to make decisions about her daughter's well-being, but not the well-being of a boyfriend, if one exists. The staff question whether to believe Amelia that she has not had sex, and decide to believe her, in part because of mutual trust developed over the years. The team thus decides again to respect Maria's decision not to tell, but to continue to encourage Maria to move toward full disclosure.

PART III

Amelia is now 15 years old and has a boyfriend, and tells her doctor that she has had sex with him, but does not always use condoms. The physician decides not to break Amelia's confidentiality about sexual activity, but tells Maria that it is time for Amelia to know her diagnosis, because Amelia is getting older and is at an age where many girls are sexually active and that she could endanger her partner. Maria objects to disclosure and says that Amelia goes to church regularly with her and would not have sex at this age.

The staff then wrestle with whether they should tell Amelia that she is HIV infected, in order to enable her to make informed decisions about whether or not she will expose her boyfriend to the sexual transmission of HIV. Should the staff encourage Amelia to inform her mother that she is sexually active, so that Maria would be more inclined to let Amelia be told about HIV? Or should the staff tell Maria that Amelia is sexually active, and then attempt to encourage her to inform Amelia of her HIV status? What rights, if any, does the boyfriend have here?

Ethically, the staff should tell Amelia at this point, though the issues here may still be complex. In particular, Amelia may not want to inform or protect the boyfriend. Disclosure alone may be beneficial in decreasing risky behavior — unsafe sex or substance use. However, youth with HIV may hesitate to use condoms, fearing that they will be seen as “unclean” by partners. Some have likely reached a level of moral development³¹ to want to avoid transmitting HIV to others. However, that desire may conflict with their wish to enhance or maintain their own psychosocial well-being or acceptance, or to appear “normal.” Additionally, disclosure might cause harm, since children may then feel angry about their HIV status, and have diminished hope for their future, leading to risky behavior without much concern about possible transmission to others, as has similarly been suggested among adults.³² For children with AIDS-related neurological impairments, care-givers and providers need to pay attention to the child's own emerging sexual curiosity and interest, ability to read social cues, and social judgment, when considering what information is appropriate to provide, given the child's level of impairment.³³ These determinations can be complicated, since HIV can also cause “adolescent-onset dementia,” with problems in processing speed, memory, executive planning, and judgment³⁴ that can contribute to transmission of the disease through sexual activity.³⁵

On balance, the staff decide at this point to inform Amelia of her HIV status and of the risk that she may have already transmitted HIV to her boyfriend, or could do so in the future if she continued having unprotected sex. They talk with Amelia about her concerns about telling her boyfriend, and help her to think about encouraging him to get an HIV test (for example, suggesting that they could go together to get tested for HIV) and to use condoms in the future. The staff inform Maria that they think that these discussions are important at this point. Maria, though with some reluctance, finally agrees to staff disclosure.

Amelia was very sad for a few weeks, and then grew angry with Maria for not having told her sooner. Amelia intimated that she always knew something was wrong, but was too afraid to

ask anyone about it. Maria became concerned that Amelia had started to drink alcohol with her friends and to smoke marijuana.

PART IV

Two months later, Amelia tells her physician that she has not informed her boyfriend that she is HIV infected. She says she doesn't want to tell him because she is ashamed and fears that he will "dump her" if she tells him.

The staff then have to decide what obligation they have to inform the boyfriend that he may have been exposed to HIV. They think they could either tell him or work closely with Amelia to have her inform him or encourage him to get tested and use condoms. The staff wonder if Maria has the right to know that her daughter is putting him at risk, and what obligation Maria has to keep Amelia from endangering him.

Here, the physician could choose to inform the boyfriend. A *Tarasoff*-like "duty to warn" permits HCWs in some states to notify sexual partners whom an HIV-infected patient is likely to have exposed.³⁶ As of 1999, 31 states had laws regarding partner notification³⁷ and *Tarasoff* "duty to warn" obligations, though these differ — for example, concerning criminalization of HIV-infected individuals who do not disclose to sexual partners — whether laws refer to "exposure alone" versus resultant infection of others, presence or absence of intent, and degrees of criminality involved (that is, from misdemeanor to attempted murder). Some states prohibit an HIV-infected person from engaging in any sexual activity with an HIV-uninfected person without disclosing, while others prohibit only unprotected penetrative acts.³⁸ In New York and many other states, legally, such disclosure to the boyfriend is currently at the doctor's discretion. Physicians can tell, but questions still emerge as to whether to do so is in the best interests of the adolescent if she opposes such notification. She may then lose trust in her providers (since her partner may say that he was notified, and he may trace the situation to her). Healthcare providers could also work with Amelia and refer her to a partner-notification program.³⁹

DISCUSSION

The exploration presented in this article illustrates how a wide range of ethical principles and other issues arise and need to be taken into consideration and balanced in this case. Yet to weigh these competing pros and cons can be difficult. Ordinarily, the mother's rights to autonomy trump those of the child, since the latter is a minor — if the mother is thought to be acting in the best interest of the child. This analysis illustrates the difficulty of developing definitive "one-size-fits-all" guidelines for these complex scenarios. Each case must be evaluated based on the specifics of the situation, consideration of the full range of concerns presented here, and the potential consequences of all options. Such an approach permits needed flexibility.

We have attempted to present the principles that should be followed when providers confront ethical dilemmas regarding disclosure of a child's HIV diagnosis. Though the articulation of specific, unequivocal rules is impossible, the range of principles highlighted here need to be considered and weighed. Though a utilitarian approach might suggest that the decision should maximize the greatest good for the greatest number, that determination is tricky at best, since the interests of the parties may conflict, and nondisclosure has significant public health consequences. This analysis also elucidates how *moral*, potentially theological, not just ethical, issues are involved. This analysis suggests potential limits of this ethical framework as well. Specifically, these principles can potentially be interpreted in varying ways that can be subjective and lead in different directions.

Clinically, some centers are no doubt more experienced than others in approaching, addressing, and following up on these issues (for example, assessing whether decisions had the anticipated effect and consequences). Hence, appropriate training for confronting these issues, and involvement of nursing staff, social workers, and psychologists is critical.

Clinicians can aid with disclosure issues in several important ways. First, providers can help parents think about disclosure as a process, rather than a single event or point in time. In this regard, caregivers may require education about the possibility of *partial* disclosure — gradually increasing the child’s understanding over time. Parents may also benefit from peer support, speaking with other caregivers concerning disclosure to an HIV-infected child — either individually or in a group.⁴⁰ The staff can try to work closely with the parent to optimize trust and minimize potential distrust that may exist. The staff may want to discuss with the mother the findings that it is best for the parent-child relationship if the parent embarks on the disclosure process at some point in the near future, rather than wait until a later point (for example, at age 18 when the provider can disclose to the child without the parent’s permission). At that later point, the child might resent the mother for not having previously divulged the information. Nonetheless, even if told by 10 or 11 years, the child may still regret not being told earlier. The staff could encourage and assist the mother to develop a future plan for disclosing. When the mother realizes the need to disclose at a concrete point in the future, she may be more inclined to overcome some hesitation or denial regarding the ultimate need for disclosure. The staff might determine whether and what other family secrets exist (for example, concerning maternal drug use, history of trading sex for drugs or money, extramarital sexual relationships, bisexuality in a father) that may underlie or contribute to the mother’s current desire for continued secrecy concerning HIV, or if the caregiver is concerned about ostracism, loss of housing or jobs, et cetera, that might result if the child discloses to others. Social workers and psychologists have skills that can help the parent cope with these issues. Unfortunately, HIV is still highly stigmatized, given its association with disenfranchised groups and sexual and drug risk behaviors, and potential lethality. Once disclosure has occurred, children often benefit from interactions with other HIV-infected children who are aware of their diagnosis to discuss coping and future disclosures with others.

Policy makers need to be acutely aware of the questions and nuances involved pertaining to HIV disclosure. Tensions arise if the child is psychologically and cognitively — but not legally — old enough to be told. The staff may then arguably, from a purely ethical perspective, be supported in disclosing, but legally be unable to disclose. Hence, potentially, policy makers could consider broadening the concept of emancipated or mature minor so that clinicians can more fully discuss the infection with offspring, even if parents object. Potentially, state laws could also become more uniform, and allow for the development of national guidelines that are more universally applicable.

This case also highlights particular questions for future research. Future studies can explore the ways children and parents view and approach these issues, and weigh these often-competing considerations; the conflicts families and providers have encountered; and their decision-making processes. Parents and clinicians no doubt vary in how they weigh some of these concerns more than others. In certain cases clinicians might think that some of these issues are more pertinent than others. Similar topics needing further investigation are whether disclosures to children at particular ages increase or decrease adherence and safer sexual practices,⁴¹ and when disclosure to children can potentially harm or benefit maternal health behaviors. This case highlights the need to develop new models for assessing and supporting children’s comprehension of HIV-related information as they age. Future studies can also elucidate children’s ability to keep such information secret.

Cultural issues are potentially critical here as well, given the ethnic diversity of families affected by HIV. A family's cultural background might influence decisions concerning disclosure of an HIV diagnosis to a child.⁴² Cultures vary in their views and practices concerning discussions of personal or taboo topics. A culturally sensitive, multi-disciplinary care approach tailored to an adolescent's needs and social circumstances is vital — using culturally sensitive language, and clear and effective interpretation.⁴³

Given the growing numbers of pediatric HIV cases worldwide, there is a tremendous need for greater understanding and guidance regarding these issues. These concerns are rapidly spreading in the developing world, where issues of autonomy, rights and responsibilities, shame, and secrecy may be framed differently. The substantial stigma in many countries can result in considerable ostracism and isolation of people living with HIV. Research is needed to understand how these issues manifest themselves in different cultural contexts.

We have attempted to shed critical light on the dilemmas posed by disclosure of HIV infection to perinatally infected children and adolescents. Given the rising spread of the pandemic, increased attention to these complexities — how ethical, psychological, medical, and legal concerns can at times conflict and need to be carefully and sensitively assessed — is critical. This attention can enhance patient care and health policy, and will be of ever-rising significance in upcoming years.

NOTES

1. UNAIDS Web site. 2004 Report on the Global AIDS Epidemic. [accessed 14 November 2005]. available at <http://www.unaids.org/bangkok2004/report.html>
2. Centers for Disease Control and Prevention. Table 14. Reported AIDS cases and annual rates (per 100,000), by area of residence and age category, cumulative through 2004 —United States". [accessed 7 April 2006]. available at www.cdc.gov/hiv/topics/surveillance/resources/reports/2004report/table14.htm
3. American Academy of Pediatrics Committee on Pediatric AIDS. Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics* January;1999 103(1):164–6. [PubMed: 9917458]
4. Wiener L, et al. Disclosure of an HIV diagnosis to children: History, current research and future directions. *Journal of Developmental and Behavioral Pediatrics*. (forthcoming)
5. Blasini I, et al. Disclosure model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and evaluation. *Developmental and Behavioral Pediatrics* 2004;25(3):181–9.
6. See note 4 above.
7. Wiener L, et al. Factors Associated with Disclosure of Diagnosis to Children with HIV/AIDS. *Pediatric AIDS and HIV Infection* 1996;7(5):310–24. [PubMed: 11361489]
8. Fins JJ, Bacchetta MD, Miller FG. Clinical Pragmatism: A method of moral problem solving. *Kennedy Institute of Ethics Journal* 1997;7(2):129–43. [PubMed: 11654986]
9. Dubler NN. Conflict and consensus at the end of life. *Hastings Center Special Report* 2005;(35):S19–S25.
10. Van Hoose, WH.; Paradise, LV. *Ethics in counseling and psychotherapy: Perspectives in issues and decision-making*. Cranston, R.I.: Carroll Press; 1979. Kitchener KS. Intuition, critical evaluation and ethical principles: The foundation for ethical decisions in counseling psychology. *Counseling Psychologist* 1984;12(3):43–55. Stadler HA. Making hard choices: Clarifying controversial ethical issues. *Counseling & Human Development* 1986;19:1–10. Haas, LJ.; Malouf, JL. *Keeping Up the Good Work: A Practitioner's Guide to Mental Health Ethics*. Sarasota, Fla.: Professional Resource Exchange, Inc.; 1989. Forester-Miller, H.; Rubenstein, RL. *Group Counseling: Ethics and Professional Issues*. In: Capuzzi, D.; Gross, DR., editors. *Introduction to Group Counseling*. Denver, Colo.: Love Publishing; 1992. p. 307-23. Sileo F, Kopala M. An A-B-C-D-E worksheet for promoting beneficence when considering ethical issues. *Counseling and Values* 1993;37:89–95.

11. Forester-Miller, H.; Davis, T. A Practitioner's Guide to Ethical Decision Making. Arlington, Va: American Counseling Association; 1996. a booklet that promotes ethical counseling practice, available without fee from the ACA, as service to the public)
12. Burris, S. Clinical Decision-Making in the Shadow of Law. In: Anderson, JR.; Barret, B., editors. Ethics in HIV-Related Psychotherapy: Clinical Decision-Making in Complex Cases. Washington, D.C.: American Psychological Association; 2000. p. 99-129.
13. GA. CODE ANN., § 24-9-47. available at <http://www.ganet.org/cgi-bin/pub/ocode/ocgsearch?number=24-9-47>
14. Habar JG. In re Storar: Euthanasia for incompetent patients, a proposed model. *Pace Law Review* 1983;3(2):351-74. [PubMed: 11658505]
15. Ibid.
16. Johnson, P. Refusal of Treatment by Children and the Mature Minor Doctrine. NYS Commission on Quality of Care, Quality of Care Newsletter. 1998-1999 [last accessed 2 May 2006]. available at www.cqc.state.ny.us/newsletter/74cclong.htm
17. Ibid.
18. Guttmacher Institute. State Policies in Brief: Minors' Access to STD Services. [last accessed 3 May 2006]. available at http://www.guttmacher.org/statecenter/spibs/spib_MASS.pdf
19. American Academy of Pediatrics Committee on Pediatric AIDS. Identification and Care of HIV-Exposed and HIV-Infected Infants, Children, and Adolescents in Foster Care. *Pediatrics* 2000;106(1):149. [PubMed: 10878167]
20. American Academy of Pediatrics Committee on Bioethics. Informed consent, parental permission, and assent in pediatrics. *Pediatrics* 1995;95(2):314-7. [PubMed: 7838658]
21. See note 5 above.
22. Marhefka SL, et al. Caregiver psychosocial characteristics and children's adherence to antiretroviral therapy. *AIDS Pt Care STDs*. (forthcoming) Mellins CA, et al. The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Pediatric Infectious Disease Journal* 2004;23(11):1035-41. [PubMed: 15545859] Mellins, CA., et al. Predictors of non-adherence in perinatally HIV-infected youths. Abstract presented at the 2006 NIMH-IAPAC International Adherence Conference; Jersey City, N.J.. March 2006;
23. Mellins et al., "The role of psychosocial and family factors," see note 22 above.
24. Mellins CA, et al. Patterns of HIV status disclosure to perinatally infected HIV-positive children and subsequent mental health outcomes. *Clinical Child Psychology and Psychiatry* 2001;7:101-14. see note 4 above
25. Johnson, SB. Managing insulin-dependent diabetes mellitus in adolescence: A developmental perspective. In: Wallander, JL.; Siegel, LJ., editors. *Adolescent Health Problems: Behavioral Perspectives*. New York, N.Y.: Guilford Press; 1995. p. 265-88.
26. Link BG, Phelan JC. Stigma and its public health implications. *Lancet* 11 February;2006 367(9509): 528. [PubMed: 16473129]
27. Clafin CJ, Barbarin OA. Does telling lies protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychiatry* 1991;16:169-91. Spinetta J, Maloney J. Death anxiety in the outpatient leukemic child. *Pediatrics* 1975;56:1034-7.
28. See note 26 above.
29. Wiener L, Battles HB, Heilman N. Public Disclosure of a Child's HIV Infection. *AIDS Patient Care STDs* 2000;14:485-97. [PubMed: 11051631]
30. Bibace R, Walsh ME. Development of children's concepts of illness. *Pediatrics* December;1980 66(6):912-7. [PubMed: 7454481]
31. Kohlberg L, Levine C, Hewer A. Moral stages: A current formulation and a response to critics. *Contributions to Human Development* 1983;10:174.
32. Crepaz N, Marks G. Towards an understanding of sexual risk behavior in people living with HIV: a review of social, psychological, and medical findings. *AIDS* 2002;16:135-49. [PubMed: 11807297]
33. Armstrong, DW., et al. Merging of neuroscience, psychosocial functioning, and bioethics in pediatric HIV. paper presented at the 110th Annual American Psychological Association; Chicago. 2002.

34. Ibid Wolters, PL.; Brouwers, P. Neurobehavioral function and assessment of children and adolescents with HIV-1 infection. In: Zeichner, SL.; Read, JS., editors. *Textbook of Pediatric Care*. Cambridge: Cambridge University Press; 2005.
35. Wiener, L.; Martin, S. Psychosocial aspects of neurological impairment in children with AIDS. In: Gendelman, H., et al., editors. *The Neurology of AIDS*. Vol. 2. New York: Oxford University Press; 2003.
36. See note 12 above, pp. 107–110.
37. Morin SF. Early detection of HIV: Assessing the legislative context. *Journal of Acquired Immune Deficiency Syndromes* 2000;25(supp 2):144–50.
38. Klitzman R, et al. Naming Names: Perceptions of Name-Based HIV Reporting, Partner Notification, and Criminalization of Non-disclosure among Persons Living with HIV. *Sexuality Research and Social Policy* 2004;1(3):38–57.
39. New York State Department of Health. HIV Reporting and Partner Notification: Summary. [accessed 27 April 2006]. available at <http://www.health.state.ny.us/diseases/aids/regulations/notification/summary.htm>
40. See note 5 above.
41. Wiener LS, Battles HB, Wood LV. A longitudinal study of adolescents with perinatally or transfusion acquired HIV infection: Sexual knowledge, risk reduction, self-efficacy, and sexual behavior. *AIDS Behavior*. 2006
42. Mason HRC, et al. Culturally sanctioned secrets? Latino men's nondisclosure of HIV infection to family, friends, and lovers. *Health Psychology* 1995;14(1):6–12. [PubMed: 7737075] Mettler, MA., et al. Racial and Ethnic Patterns of Disclosure to Children with HIV. paper presented at the American Psychological Association's Annual Conference; Chicago, Illinois. August 1997;
43. Munet-Vilaro F. Delivery of Culturally competent care to children with cancer and their families — The Latino experience. *Journal of Pediatric Oncology Nursing* 2004;21(3):155–9. [PubMed: 15296045]

Table 1

Ethical Principles Involved in Disclosure of HIV Status to a Minor

Principle	Arguments in Favor of Disclosure	Arguments Against Disclosure
Autonomy	<ul style="list-style-type: none"> • Child has a right to know what is inside his or her own body 	<ul style="list-style-type: none"> • Parent has a right to decide • Parent will have to deal with consequences of disclosure • Parents generally act in the child's best interest • Rights of parent outweigh those of HCW
Beneficence	<ul style="list-style-type: none"> • Disclosure may empower the child • Disclosure may have medical benefits: <ul style="list-style-type: none"> – Helping with adherence – Encouraging/increasing safer sexual practices – Helping mothers adherence and healthcare • Disclosure may have psychological benefits: <ul style="list-style-type: none"> – Increasing use of psychotherapy/social services by mother and child – Reducing burden of secrecy for parents – Enhancing relationships and bonding between parent and child • Disclosure can facilitate parent receiving additional help from HCWs 	<ul style="list-style-type: none"> • Non-disclosure provides some benefit, protecting child from burden
Non-Maleficance	<ul style="list-style-type: none"> • Disclosure can prevent deception of child 	<ul style="list-style-type: none"> • Disclosure may cause medical harms: <ul style="list-style-type: none"> – Decreasing adherence • Disclosure may: <ul style="list-style-type: none"> – Burden the child psychologically, impairing self-esteem, and increasing anxiety and depression – Increase marginalization/stigma of child and family – Cause parents to feel guilty • Child might then disclose the information to others, hurting the family as a whole
Autonomy	<p style="text-align: center;">Additional Issues that arise if a minor is sexually active</p> <ul style="list-style-type: none"> • Sexual partner has a right to know of his or her risk 	<ul style="list-style-type: none"> • Offspring has a right to decide whether to disclose or not to partner
Beneficence	<ul style="list-style-type: none"> • Disclosure might prompt safer sex 	
Non-Maleficance		<ul style="list-style-type: none"> • Withholding of information can contribute to partner becoming infected
Justice	<ul style="list-style-type: none"> • Public health concerns: <ul style="list-style-type: none"> – Offspring may have additional partners over time to whom he or she can spread HIV – Sexual partners have a right to know risks 	