When Parents Reject Interventions to Reduce Postnatal Human Immunodeficiency Virus Transmission

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In a recent Oregon case, the state successfully sued for custody of an infant to prevent his human immunodeficiency virus (HIV)–infected mother from breastfeeding him and to require antiretroviral prophylaxis. As more HIV-infected women give birth, pediatricians may increasingly face dilemmas when parents reject medical recommendations to forgo breastfeeding and to administer antiretroviral prophylaxis to the infant. Such disagreements create ethical dilemmas because pediatricians have an obligation to both protect the infant and respect parental decision making. Pediatricians need to balance these obligations in deciding whether to ask the courts to intervene on the infant’s behalf. To that end, we analyze the legal and ethical issues that arise when an HIV-infected mother refuses interventions to reduce neonatal transmission of HIV to her infant, provide an approach for addressing these disagreements, and present illustrative scenarios in which pediatricians should, may, and should not seek a court order to intervene.

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Kathleen Tyson tested positive for human immunodeficiency virus (HIV) during a prenatal test.1 Although Tyson initially accepted treatment with zidovudine, she stopped treatment after she and her husband became persuaded that HIV does not cause acquired immunodeficiency syndrome (AIDS) and that zidovudine is unsafe and ineffective.1-3 Accordingly, Tyson refused zidovudine for herself during labor and for her son, Felix, after delivery.2,3 Tyson began to breastfeed Felix in the hospital. On the night he was born, a state social worker came to Tyson’s room with an armed police officer to persuade her not to breastfeed Felix. When Tyson refused, the social worker gave the parents a summons to appear in court and a protective order for the newborn.4

Within days of Felix’s birth, a custody hearing was held. The Tysons agreed to abide by a court order to administer zidovudine prophylaxis to Felix and to bottle-feed. The court allowed them to retain physical custody of Felix but awarded the state legal custody and medical decision-making authority on Felix’s behalf.4 Felix tested negative for HIV at birth, 1 month, and 6 months.5,6 The state continues to monitor Felix to ensure compliance with the court’s order.7 While the custody case was pending, Tyson pumped her milk and froze it so she would be able to breastfeed Felix if the order were lifted.1

Mother-to-child transmission (MTCT) of HIV can be significantly reduced by antiretroviral therapy to the mother and infant and by forgoing breastfeeding.8-15 However, as the Tyson case shows, some seropositive, pregnant women may refuse antiretroviral therapy during pregnancy, labor, and delivery and/or refuse antiretroviral prophylaxis for the infant and insist on breastfeeding. Such refusals raise ethical dilemmas because the well-being of the infant may conflict with parental preferences for child rearing and medical care. Although courts have ordered such interventions, intervening on the fetus’s behalf before birth over the woman’s objection is...
ethically problematic because it requires bodily invasion of the mother. After birth, it becomes possible to provide interventions directly to the infant. The ethical principle of beneficence, which is fundamental in pediatrics, supports the urge to intervene postnatally to administer antiretroviral therapy to HIV-exposed infants and to require bottle-feeding because infants cannot protect themselves and these interventions are effective and generally accepted. However, the same principle encourages pediatricians to respect parental choices because parents are the most appropriate arbiters of their children’s best interests. To address this dilemma, we first analyze the legal and ethical issues that arise in such cases. Although intervention in such cases may be permissible under legal and ethical principles, appeal to these principles alone does not resolve the dilemma. Accordingly, we provide an approach for addressing these disagreements that involves clarifying the medical risks and benefits, clarifying the social risks and benefits, understanding the parents’ reasons for refusal, and exploring available options. Finally, we present illustrative scenarios in which pediatricians should, may, and should not seek a court order to intervene on the infant’s behalf.

ETHICAL BACKGROUND

Ethically, as well as legally, parents are presumed to be the appropriate decision makers for their children. In the United States, parents are granted considerable autonomy to raise children in accordance with their values and beliefs, with the expectation that love will guide parents to make decisions in their children’s best interests. Pediatricians typically defer to parental choices. However, when parental choices threaten the child’s well-being, parental power may be limited.

Because infants cannot protect themselves, pediatricians have a special obligation to advocate on behalf of their patients and to take steps to remove or minimize harms to them. When parents cannot be persuaded to accept interventions to reduce the risk of HIV transmission to the infant, there is a fundamental conflict regarding the infant’s best interests. The pediatrician cannot act to benefit the infant without overriding the parents’ preferences regarding the care of their infant. To preserve children’s right to an open future, so to preserve children’s right to an open future, society sometimes intervenes to prevent parents from risking their children’s lives for the sake of values the children may not agree with when they reach maturity. Although pediatricians should be cautious about seeking to override parental decision making, in some cases it may be necessary to reduce the risk of HIV transmission and to protect the child’s future autonomy interests.

LEGAL BACKGROUND

The law generally recognizes parents’ authority over their children’s medical decisions, including the right to refuse recommended medical treatment, sometimes even in life-threatening situations. Nevertheless, in some instances, courts have legal authority to declare a child medically neglected, override parental decisions, and order needed medical treatment to protect the child from serious harm. Such cases often are initiated by the child’s physician. Parents who agree to comply with court-ordered treatment may retain physical custody of their children, although they lose legal authority to make medical decisions.

Although court decisions in medical neglect cases are sometimes inconsistent among, and even within, jurisdictions, some general observations can be made. Courts generally order medical treatment over parental objections when the treatment is very likely to save the child’s life, has few medical risks, and is short-term. A common example is blood transfusions of children of Jehovah’s Witnesses. Courts also are likely to order more invasive or long-term treatment, such as surgery or chemotherapy, when the treatment is necessary to cure a life-threatening condition and is highly likely to be effective.

Courts generally are reluctant to order treatment over parents’ objections when the underlying condition is not life-threatening, there is a low probability of successful treatment, or the treatment itself is dangerous, burdensome, or long term. Courts have also considered whether the recommended treatment is widely accepted, whether the child is symptomatic, and the basis of the parents’ objections, and whether the recommendation is supported by scientific consensus. Although religious objections to medical treatment are given substantial weight, they are not dispositive.

The one reported case involving prevention rather than treatment followed the same approach. Postnatal zidovudine prophylaxis and forgoing breastfeeding significantly reduce the risk of transmitting an infection that will ultimately prove fatal, are considered safe, and are widely accepted. Accordingly, cases of parental refusal of prevention measures share the key features of cases in which courts have ordered treatment over parental objections. It is therefore likely that, in the absence of a compelling justification for not following prevention measures, courts will order HIV-infected mothers to administer prophylaxis to their infants and to bottle-feed, as the Tyson court did.

RESPONDING TO PARENTAL REFUSAL OF HIV PREVENTION MEASURES

When parents cannot be persuaded to follow recommended measures to reduce the risk of neonatal HIV transmission, the pediatrician needs to consider whether to go to court to override that refusal. We next analyze the relevant considerations and suggest how to balance them.

CLARIFY THE MEDICAL BENEFITS AND HARMS

Clinical decision making involves a balancing of potential benefits against risks. It is impossible to remove all risk of HIV transmission, even when all prevention measures are taken. Accordingly, the pediatrician needs to determine whether the potential benefit from prevention measures after the child is born justifies seeking court authority to override the parental decision. The courts have not quantified what level of risk justifies overrid-
ing parental decision making. Pediatricians therefore must rely on their own judgment. Because parents are granted considerable discretion to make decisions for their children, a pediatrician should apply a stricter standard for asking the courts to override parental refusal of preventive measures than for recommending such measures to the parents in the first place.

In making the risk-benefit assessment, the pediatrician must consider the magnitude and probability of the potential benefit and harm, including the risk of transmission and the effectiveness, invasiveness, and side effects of prophylaxis. Transmission of HIV from mother to infant can occur in utero, during labor and delivery, and through breastfeeding. When antiretroviral therapies are administered prophylactically to the woman during pregnancy, labor, and delivery and administered to the infant in the postpartum period and further exposure is avoided by bottle-feeding, the risk of MTCT of HIV may be reduced from approximately 25% to between 2% and 8%.5-14

Even without prenatal antiretroviral therapy of the mother, data from a retrospective, observational study suggest that early postnatal zidovudine prophylaxis for the infant may reduce the risk of MTCT. Observed transmission rates for infants who received zidovudine within 48 hours after birth were approximately 9% compared with approximately 27% for infants receiving no antiretroviral prophylaxis. Some infants may already have been infected before birth, and, therefore, administration of prophylaxis and bottle-feeding will not benefit these infants. However, the presence of maternal antibodies makes it difficult to identify these infants at birth in routine clinical practice.

Zidovudine, the antiretroviral drug proven effective in reducing MTCT of HIV, generally is considered safe for the infant. Recent studies have found no serious short-term adverse effects in children who received zidovudine prophylaxis in utero and postnatally.

Data from outside the United States indicate that bottle-feeding instead of breastfeeding can also reduce MTCT of HIV even if antiretroviral therapy is not administered. A meta-analysis and several cohort studies have estimated the risk of HIV transmission attributable to breastfeeding to be between 7% and 14%. A randomized clinical trial in Kenya showed that bottle-feeding instead of breastfeeding reduces the risk of transmission from 37% to at least 21%. Given the many benefits of breastfeeding, it is counterintuitive that breastfeeding could be harmful. However, for HIV-infected women, the risk of MTCT of HIV makes bottle-feeding a safer alternative when clean water is available.

The pediatrician must also consider how the mother’s clinical situation affects the risk of transmission. For example, high maternal viral load and low maternal CD4 cell count correlate with increased vertical transmission. There would thus be stronger grounds for seeking court authority to override the mother’s refusal of zidovudine and bottle-feeding if she has a high viral titer. Because the data concerning postpartum prophylaxis and the risk attributable to breastfeeding, particularly in the United States, are limited, some pediatricians may question the effectiveness of these interventions. Nevertheless, many pediatricians would reasonably conclude that, in general, the medical benefits of zidovudine prophylaxis and forgoing breastfeeding outweigh the medical risks.

**CLARIFY THE SOCIAL BENEFITS AND HARMS**

Overriding parental medical decision making may carry substantial psychosocial costs. Court proceedings for medical neglect may jeopardize the parent-child relationship in several ways. If the infant is removed from the parents’ care, the foster care system may fail to meet the basic medical, psychological, and emotional needs of the child entrusted to it. In addition, the threat of losing custody of their infant may cause parents to compromise deeply held personal beliefs and values to comply with recommended medical care.

Attempts to override parents’ medical decisions also may harm the pediatrician-parent relationship and compromise future medical care. Parents may come to mistrust both the pediatrician who initiated neglect proceedings and physicians in general. Parents also may be less forthcoming in future dealings with the medical system or may avoid it altogether, thereby compromising the child’s health. Furthermore, pediatricians commonly find that if they work with parents over time, they can persuade parents to accept interventions the parents initially rejected, whereas an adversarial stance may irreparably damage the relationship.

Other social harms may result from the family’s cultural and social context. In some cultures, breastfeeding is the norm and may play an important symbolic role in conveying social status to mothers. For instance, the Koran dictates that Muslim women breastfeed their husbands’ children for 2 years. In such cultures, a woman may feel pressure to breastfeed and risk rejection or abandonment by her spouse or family if she does not. Similarly, compliance with prevention measures could lead to unintended disclosure of the mother’s HIV status to her partner or other family members. Such disclosure could subject the mother and infant to violence or loss of housing and support.

Giving up breastfeeding also may weaken the mother-infant relationship. Breastfeeding provides medical, psychological, and economic benefits for both the mother and infant. In addition, breastfeeding helps mother-infant bonding and attachment. Although many American women do not breastfeed, some women are strongly committed to breastfeeding.

Finally, monitoring the parents’ compliance with preventive measures may be intrusive and disruptive. Breastfeeding is fundamentally different from most other medical interventions. Feeding takes place multiple times per day in the privacy of the parents’ home. It would therefore be easy and convenient for parents to promise not to breastfeed and then do what they want. Effective monitoring would require constant surveillance of the family in its home. Accordingly, less effective forms of monitoring must be adopted. For example, the state of Oregon monitors the Tysons’ compliance with the custody order through weekly visits.
UNDERSTAND THE PARENTS’ REASONS FOR REFUSAL

Pediatricians should probe whether parents’ refusal of prevention measures is an informed decision. First, the mother may have misunderstandings that can be corrected. For example, an HIV-infected woman who intends to breastfeed may be following the advice of a clinician who is unaware of her HIV status. Parents concerned about short-term adverse effects may be reassured by evidence of safety.

Second, a discussion of the parents’ reasons for refusing prevention measures may identify social and cultural factors to be addressed. In some cases, the mother may face serious harms, such as domestic violence, rejection, or abandonment, if she does not breastfeed. The pediatrician may support the mother’s decision after understanding these social risks. However, the fact that a parent’s decision has a strong cultural basis does not require the pediatrician to accept it. In other situations, pediatricians are urged to oppose cultural practices that cause harm and suffering to children, such as female genital mutilation or traditional remedies that burn an infant’s skin.63,64

Finally, discussions may reveal that the parent is incapable of making an informed decision because of incapacitating psychiatric illness, on-going effects of substance abuse, or a false belief. A false belief is one that is demonstrably false and is material to the treatment decision.65,66 For example, a patient’s denial of a true cancer diagnosis may prevent her from making an informed treatment decision. Unconventional beliefs, including religious beliefs, are not necessarily false beliefs. Respect for a parent’s decisions does not extend to decisions that are the product of illness or mental incapacity or where the decision cannot be informed. When the parent is not capable of making an informed decision, the pediatrician has a clear ethical obligation to protect the infant.25,65

The Tysons refused to follow medical advice because they do not believe that HIV causes AIDS or is otherwise harmful. In response to South African President Thabo Mbeki’s similar denial of the causal link between HIV and AIDS, hundreds of distinguished AIDS researchers recently produced the Durban Declaration, which documents the overwhelming scientific evidence contradicting this position.67 Because the Tysons cannot be dissuaded from this false belief, it is appropriate to appropriate the courts to override their decision to benefit their infant. However, they also objected to prophylaxis because of concerns about the toxicity of zidovudine. Although zidovudine prophylaxis to infants generally is considered safe, there can be short-term adverse effects, and the long-term effects are not known.62 Hence, the refusal of zidovudine prophylaxis was not based on a false belief. In these unique circumstances, it might have been appropriate to override only the decision based on a false belief, that is, to require bottle-feeding but not require zidovudine prophylaxis.

Some parents may initially be unable or unwilling to articulate the reasons for their decision. In such cases, it is incumbent on the pediatrician to work with the parents to attempt to understand the decision. If necessary, and with the parents’ permission, the pediatrician should involve other members of the medical team, family members, or friends to facilitate the discussion.

EXPLORE AVAILABLE OPTIONS

The pediatrician should consider whether there are any options to mitigate the risk to the infant that the parents would accept, even if the maximum reduction is not achieved. Pediatricians have successfully used this approach to benefit children in other circumstances. Some options include administration of a shorter or less intensive drug regimen. The benefits of breastfeeding might be achieved through use of banked donor breast milk.68,69 Pasteurization of banked breast milk destroys HIV but preserves most of the milk’s beneficial qualities.69 There have been no reported cases of HIV infection from banked breast milk where donors are screened for HIV.68,69 Alternatively, intimate contact during bottle-feeding, such as skin-to-skin contact and wearing the infant in a sling or other carrier, might provide some of the benefits of breastfeeding.60,61 In cases of domestic violence, the pediatrician should involve social workers or domestic violence assistance programs. If the woman can be placed in a safe environment, she may agree to HIV prevention measures.

THE IMPORTANCE OF DISCUSSIONS WITH PARENTS

A plan developed jointly by the parents and pediatrician is preferable ethically to a course imposed on the family. In discussions, the parents may change their minds, a fresh approach may be identified, or a compromise may be forged. The discussions necessary to resolve the dispute take time. However, delay in intervention may allow for additional exposure and, therefore, additional risk to the infant. Accordingly, discussions should begin whenever possible before delivery. The time for discussions may be extended if the mother agrees not to breastfeed for a short period but pumps to establish her milk supply.

The pediatrician should consider carefully whom to involve in the discussions. Because of potential social harms, the pediatrician should speak with the mother alone until it is established that including the father in the discussions will not place the mother or infant at risk. However, if the mother agrees, involving a trusted family member, friend, other medical professional, religious adviser, or hospital ethics committee may facilitate discussions.

This task is a heavy one for busy pediatricians, particularly when faced with a possibly irrational parent. Nevertheless, this is a task pediatricians have traditionally assumed with other complicated medical and psychosocial issues.

WHEN THE DISPUTE REMAINS UNRESOLVED

When the dispute remains unresolved despite best efforts to negotiate a resolution with the parents, pedi-
tricians must determine whether to request a court order to treat the infant over the parents’ objections. This determination requires the pediatrician to balance the 4 factors we have identified. Although the outcome will depend on the specific facts of each case, the following hypothetical scenarios illustrate situations in which a pediatrician (1) should, (2) may, and (3) should not seek a court order. The Table summarizes our recommendations. Regardless of the decision, the pediatrician should attempt to continue to work with the parents.

**ETHICALLY MANDATORY TO SEEK A COURT ORDER**

A schizophrenic woman known to be infected with HIV is taken to the emergency department after delivering a neonate at a friend’s apartment. She stopped taking her psychiatric and antiretroviral medications and is hallucinating and delusional. Her last viral load was 20000 copies/mL. She refuses administration of antiretroviral medication to her infant and insists on breastfeeding.

Because her severe psychiatric illness renders her incapable of making informed medical decisions, there is an obligation to intervene to benefit both the mother and infant. The pediatrician should seek a court order authorizing postpartum HIV prevention measures when the parent is incapable of making an informed decision because of severe psychiatric illness or a false belief that is essential to the medical decision. When the parent cannot make an informed refusal, the medical benefits should be dispositive. With a seriously impaired parent, the state may need to take physical custody of the infant.

**ETHICALLY PERMISSIBLE TO SEEK A COURT ORDER**

An HIV-infected woman has never undergone antiretroviral therapy. She has a viral load of 12000 copies/mL but a CD4 cell count of 450/µL and generally feels healthy. Because she has done well to date without medications, she refuses prophylaxis for her infant and antiretroviral therapy for herself. She also cannot be persuaded to bottlefeed, believing she will continue to beat the odds.

This woman’s clinical situation creates a considerable risk of transmission to her infant. In the absence of antiretroviral medications, bottle-feeding instead of breastfeeding has been shown to reduce MTCT of HIV from 37% to 21% in a cohort of African women. Moreover, the woman has not articulated a strong basis for her decision. Under these circumstances, there are strong grounds to ask a court to order the woman to forgo breastfeeding her infant and to administer zidovudine prophylaxis. Many pediatricians will feel they should seek a court order in such a case, and it is ethically permissible to do so. However, some pediatricians, based on their experiences, may reasonably judge that the risk to the infant is not high enough to override parental authority or that their best chance of protecting the infant in the long term is to continue to work to persuade the woman to accept prevention measures. It is ethically permissible for them not to seek a court order.

**ETHICALLY IMPERMISSIBLE TO SEEK A COURT ORDER**

An HIV-infected Muslim woman insists on breastfeeding her infant because it is expected in her culture. If she does not breastfeed, she fears that her family will discover her infection and reject her and the infant. She is taking combination antiretroviral therapy and has had an undetectable viral load throughout her pregnancy. She agrees to give antiretroviral prophylaxis to her infant and also agrees to reconsider her decision to breastfeed if her viral titer becomes detectable. She feels that early weaning is less likely to raise suspicions than not breastfeeding would.

This woman’s social situation presents a serious risk of harm to her and her infant. Although she is not doing everything she could, the woman has taken steps to significantly reduce the risk of transmission to her infant. By taking combination antiretroviral therapy for herself and giving zidovudine prophylaxis to her infant, she has reduced her risk of transmission to less than 2%. Although no data exist, there is reason to believe that combination therapy may offer a protective effect during breastfeeding. Moreover, the woman has suggested a means of protecting the child within the constraints of her social circumstances. Accordingly, the pediatrician should not seek a court order to override her decision.

**CONCLUSIONS**

Parental refusal of measures to reduce the risk of MTCT of HIV creates an ethical dilemma for pediatricians, who have an obligation to both protect the infant and respect parental decision making. Pediatricians have an obligation to attempt to persuade the parents to accept prevention measures and, in some circumstances, to ask the courts to intervene. Because a court likely will find a pediatrician’s opinion highly persuasive, pediatricians should proceed carefully before making such a request. Compelled interventions to further reduce risk of transmission may create greater risks to an infant who is at low risk for HIV transmission than not intervening, includ-
When parents refuse measures known to reduce transmission of HIV from mother to infant, pediatricians face difficult ethical dilemmas about whether to ask a court to override the parents’ decision. Physicians have ethical and legal obligations not only to respect the choices parents make for their children but also to act in the best interests of the child. Appeals to ethical and legal principles alone will not help pediatricians resolve this dilemma. In this article, we provide an approach for addressing parental refusals of prevention measures that involves clarifying the medical risks and benefits, clarifying the social risks and benefits, and understanding the parents’ reasons for refusal.

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