

Rethinking Mandatory HIV Testing During Pregnancy in Areas With High HIV Prevalence Rates: Ethical and Policy Issues

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We analyzed the ethical and policy issues surrounding mandatory HIV testing of pregnant women in areas with high HIV prevalence rates. Through this analysis, we seek to demonstrate that a mandatory approach to testing and treatment has the potential to significantly reduce perinatal transmission of HIV and defend the view that mandatory testing is morally required if a number of conditions can be met.

If such programs are to be introduced, continuing medical care, including highly active antiretroviral therapy, must be provided and pregnant women must have reasonable alternatives to compulsory testing and treatment. We propose that a liberal regime entailing abortion rights up to the point of fetal viability would satisfy these requirements.

Pilot studies in the high-prevalence region of southern African should investigate the feasibility of this approach (*Am J Public Health*. 2007;97:XXX-XXX. doi:10.2105/AJPH.2006.093526)

IN 2005, BETWEEN 36.7 AND 45.3 million people were estimated to be HIV positive. Between 4.3 and 6.6 million persons were infected with HIV in that year alone, and approximately 3.1 million deaths were attributed to AIDS. About 35% of newborns born to HIV-infected women contract the virus from their mothers if efforts to prevent mother-to-child transmission are not in place. In 2004, for example, this mode of transmission resulted in up to 2.8 million HIV-infected children worldwide. More than 600 000 children were newly infected with HIV during 2005, and it is estimated that a similar number of children died of AIDS in the same year.¹

A landmark 1994 multicenter trial conclusively demonstrated the efficacy of using antiretroviral therapy to reduce mother-to-child transmission of HIV,² showing a 67.5% relative reduction in mother-to-child transmission with the use of zidovudine. Since then, researchers have investigated the effects on mother-to-child HIV transmission of different drug regimens, shorter courses of drugs, breastfeeding, delivery by caesarian section, vitamin supplements, and treatment of newborns whose mothers did not receive antiretroviral therapy.

This intensity of research into ways of reducing vertical transmission of HIV has led to a focus of attention on the obstetric care of pregnant women in high-prevalence regions. Treatment is

contingent upon the pregnant woman seeking antenatal care, being screened for HIV, and agreeing to medical intervention. The continuing high number of children with vertically acquired HIV attests to failures at various stages of this process. The scale of the problem demonstrates individual tragedies on an overwhelming scale and a threat to the public health of the communities in question.

Pregnant women who seek antenatal care are typically offered 1 of 2 types of HIV testing, referred to as *opt in* and *opt out*. With opt-in testing, the health worker offers the HIV test, and if the woman seeking antenatal care elects to have the test, it is accompanied by pretest counseling and voluntary first-person informed consent. In most developed countries, HIV testing of pregnant women is voluntary and requires informed consent and elaborate counseling procedures.³ Whether opt-in testing should be applied in developing countries with substantially higher HIV prevalence rates has been called into question⁴; in most developing countries, antenatal clinics are short staffed and counselors overburdened.⁵

Opt-out testing involves the woman being told that HIV testing will be carried out along with other routine tests unless she refuses. Adoption of the opt-out approach to prenatal HIV testing has resulted in a marked increase in uptake of the test.⁶ In Canada, provinces using the opt-out approach show almost universal

uptake, whereas testing rates in provinces using opt in are only 50% to 60%.⁷ In Alabama, uptake increased from 75% to 88% after a switch from opt-in to opt-out testing.⁸

It is significant that making it more difficult to avoid testing translates into larger numbers of pregnant women finding out about their HIV status. In turn, they and their health care providers are able to make informed choices about appropriate courses of action. In Ivory Coast, fewer than 50% of pregnant women who test HIV positive return to receive treatment, which would lower rates of mother-to-child transmission.⁹ An analysis of pregnant women in the United Kingdom who refused testing showed that these “refusers” were twice as likely to be infected with hepatitis B virus as those who agreed to be tested.¹⁰

A study conducted at the South African Johannesburg Hospital determined that the HIV seroprevalence rate among women who refused routine antenatal HIV screening was a staggering 44%. This rate was higher than the HIV prevalence in the general antenatal population at the hospital, which was 29.4%.¹¹ The women who refused HIV testing agreed to take part in this anonymous study if their HIV status was not disclosed to them. Women may have refused testing because they believed that they were not at risk or, conversely, that their fear of being at risk would be confirmed by the test. Other crucial factors may have

been fear of the stigma associated with HIV/AIDS and the possibility of being shunned by one's community or worse (e.g., harassment, loss of livelihood, eviction, murder).¹²

Failure to undergo testing for HIV could also be related to external factors such as poverty and poor access to clinics (the testing model proposed here would apply to pregnant women who have access to antenatal clinics). In a meta-analysis of recent studies of HIV/AIDS-related stigma in developing countries, it was concluded that much-feared negative community or partner responses are far less common than women assume.⁵ Indian investigators concluded that actual stigma experienced by women with HIV infection is lower (reported by 26% of women) than the fear of being stigmatized (reported by 97%).¹³ This suggests that many women are probably overly concerned about stigma and that, in reality, their likelihood of being stigmatized is substantially smaller than they think it is.

Confidential HIV tests as well as free or affordable drugs aimed at preventing mother-to-child transmission of HIV are accessible to an increasing number of pregnant women in developing countries. The price paid by HIV-infected newborns for their mothers' failure to undergo testing and treatment is very high; the average life expectancy of an HIV-infected newborn who does not receive state-of-the-art medical care is about 2 years.¹⁴ During this time the newborn suffers from a range of life-threatening illnesses; the average HIV-infected newborn lives a short life of low quality.

In South Africa, where the HIV antenatal prevalence rate is approximately 30%, we estimated

that a 25% increase in testing would result in an additional increase in HIV detection of 7.5%. Use of the ACTG076 regimen (antepartum and intrapartum zidovudine for the mother and 6 weeks of treatment for the newborn) would result in HIV being averted in 1.1% to 1.5% of all newborns. Given South Africa's 1 million births per year, 11 000 to 15 000 infections could be prevented (Mike Urban, National Health and Laboratory Services, Johannesburg, South Africa, written communication, September 2006).

Here we address an important ethical and policy issue, namely the obligations of pregnant women and authorities in reducing the number of infants born with HIV infection in high-prevalence countries where medications aimed at preventing mother-to-child transmission are available to individuals irrespective of their capacity to pay. Recent bioethical analyses diverge from the developed world consensus on this issue and argue that both compulsory testing and compulsory treatment could be defensible in a public health emergency such as that of AIDS.¹⁵ The initial developed world consensus stemmed from the wide acceptance of arguments suggesting that women have an absolute right to control their own body and that only very few infections of newborns would occur as a consequence of some infected women's choice not to undergo testing.¹⁶

Botswana, a southern African country, has adopted the opt-out system of HIV testing for all patients who seek care at health care facilities, including pregnant women. One of the objectives of such programs is to reduce the number of infected newborns.

Botswana and other countries with similar programs offer free (but voluntary) highly active antiretroviral therapy (HAART) to parents for as long as clinically indicated in an effort to ensure that children have surviving parents capable of looking after them. This is a direct response to the ever-growing number of AIDS orphans on the African continent. In a dramatic turnaround of the developed world status quo, Clark concluded his analysis of the problem by suggesting that "the prevention of perinatal HIV transmission in Botswana, because of the availability of antiretroviral therapy for infected mothers and their children, greatly outweighs the burdens of the possible violation of the pregnant woman's privacy."^{15(p7)}

Our argument in favor of mandatory testing and treatment of HIV-infected pregnant women in areas with high HIV prevalence rates depends on a number of conditions being met: the women in question would have had voluntarily chosen to carry the fetus to term; they would have had a reasonable alternative to this course of action (e.g., abortion at least until the point of fetal viability); and continuing voluntary treatment with HAART would be available to them. The confidentiality of the women's HIV status should ideally be maintained during as well as after their pregnancy. Delivery mechanisms should be developed that allow testing and treatment and ensure continuing confidentiality. However, ultimately the latter condition is not imperative.

LIABILITY FOR HARM TO AN UNBORN CHILD

Courts have often been confronted with the problem of

conflict between the rights to autonomy, privacy, and freedom of movement of pregnant women and the prevention of harm to fetuses. The Canadian case of *Winnipeg Child and Family Services v DFG* concerned a glue addict who had given birth to 2 children with abnormalities.¹⁷ Upon her becoming pregnant for the fourth time, the child care services department applied for an order placing her in a treatment center to manage her withdrawal and monitor the pregnancy. The lower court granted the order "because the court should only step in when it is certain that the mother intends to proceed to give birth."¹⁷

The majority in the appeals court overturned the order on the basis that the fetus did not have legal status while in utero and that the pregnant mother could not therefore be forcibly held for treatment. An infant acquires rights only upon being born alive. The court also expressed concern that penalizing pregnant women might deter them from seeking antenatal care. Dissenting judges Sopinka and Major were in favor of the intervention to prevent harm to the fetus:

this interference is always subject to the woman's right to end it by deciding to have an abortion. . . . When a woman chooses to carry a fetus to term, she must accept some responsibility for its well-being and the state has an interest in trying to ensure the child's health.¹⁷

Canadian law does backdate fetal rights if the child is born alive. This means that a child born alive who suffered harm before birth can recover compensation for damages, even though the harm occurred at a time

when he or she was not legally a person. In one instance, a mother who withheld her HIV status from medical staff and subsequently gave birth to an HIV-positive child was charged with criminal negligence causing bodily harm and failure to provide the necessities of life (i.e., proper care, protection, shelter, food).¹⁸ In contrast, civil courts have ruled that a child cannot sue his or her mother for injuries incurred during pregnancy as a result of the mother's conduct (e.g., *Dobson v Dobson*,¹⁹ a Canadian case in which a child sued his mother for the injuries he incurred as a consequence of her negligent driving while pregnant with him).

In Canada, child protection legislation has also been used to forcibly treat pregnant women in an effort to prevent harm to the fetus. In the United States, health and social services authorities obtain court orders for this purpose.²⁰ Given that a competent person is allowed to refuse even life-saving treatment, some courts appear to be giving recognition to the fetus as a separate patient, although technically, as mentioned, infants acquire rights only after being born alive. US social services agencies have removed children from the custody of a pregnant woman who has exposed a fetus to harm through substance abuse and brought charges of inter alia child abuse, neglect, reckless endangerment, and manslaughter.²¹

The United States has seen a wave of "fetal protectionism" in the form of laws criminalizing prenatal harm through abuse of alcohol and illegal drug use, as well as legislation allowing double homicide charges to be brought against someone who harms a pregnant woman and a

child she wished to carry to term. In South Africa and Australia, legal personhood of the fetus can be backdated if the child is born alive and has a legal claim that arose while he or she was in utero. Although it is beyond the scope of this article to discuss wrongful life litigation and disability rights arguments against prenatal screening, we wish to point out that a number of legal systems are attempting to find a balance between discouraging prenatal harm and preserving the right to termination of pregnancy.

THE TRADITIONAL VERSUS THE CURRENT DEBATE

In this debate, it is worthwhile to recall strategies deployed in the abortion controversies and reflect on the question of how the current debates do and do not relate to those bitterly fought issues. Arguments by various authors have attempted to place the suggestion that compulsory testing should be introduced for women in high-prevalence areas in the same category as the view that abortion is always wrong.²² The suggestion here is that the fetus's life is of greater importance than the woman's right to control her own body. This analysis overlooks the fact that the pro-test argument is not necessarily about fetal life but about that of the newborn itself. In the current controversy, it is logically possible to hold a pro-choice view in the abortion debates and a compulsory testing and treatment view.

The traditional debates on the issue of interfering with women's reproductive choices were squarely focused on the moral status of embryos and the question of whether or not abortion is

morally acceptable. A variety of hotly contested marker events were proposed after which abortion was argued to be unethical.²³ The abortion debates effectively address the question of whether fetuses have an overriding moral claim on women to carry them to term. There is at least 1 similarity between these debates and the current debate, namely the question of whether an abortion might be an acceptable solution for an HIV-infected pregnant woman trying to avoid giving birth to an infected newborn. This is comparable to traditional discussions about the moral acceptability of abortion in cases in which the newborn is at serious risk of an inheritable genetic illness.

That, however, is where the similarity ends. Although this is not the place to argue²⁴⁻²⁶ our position on the abortion controversy, we consider it important to stress that, from a policy perspective and from an ethics perspective, logically it is perfectly feasible to hold a liberal point of view in the abortion controversy and to favor a restrictive point of view on the issue of mandatory HIV testing of pregnant women in areas with high HIV prevalence rates.

The current debate on this issue started in developed countries, most vigorously in the United States, after a 1994 study demonstrated that zidovudine, when given to infected pregnant women and newborns, would reduce perinatal transmission of the virus. After years of controversy, the scales seem to be tipping slowly toward the mandatory approach we advocate. Several US states advocate mandatory testing of newborns, and recently, additional states have moved toward introducing legislation making

HIV testing of pregnant women mandatory.²² The prevalence of HIV is several magnitudes lower in the United States than it is, for instance, in Botswana, yet even there liberal attitudes are beginning to be replaced by policies designed to achieve better (public) health outcomes.

Feminist activists in developed countries have argued against compulsory testing and treatment, criticizing a supposedly "maternal ideology [according to which] good mothers engage in acts of self-sacrifice and self-abnegation, always putting the interests of their children before their own."^{22(p349)} It is unclear to us how HIV testing and acceptance of medication that not only reduces perinatal HIV transmission rates but also preserves mothers' lives can reasonably be considered self-sacrificial acts. The critics have also reconstructed the dispute as akin to the traditional conflict between fetal and maternal interests, that is, the fetus's supposed interests weighed against the pregnant woman's interest in maintaining control over her own body.

This argument is flawed in a crucial respect. What if we granted such women the right to have an abortion instead of undergoing testing? If pregnant women decide voluntarily not to have an abortion, the issue is no longer about fetal rights but clearly about an infant they want to bring to term. Moral obligations toward improving the newborn's chances of living a life worth living can be derived from the pregnant women's decision that the infant should come into being (i.e., the decision not to abort). The decision to simultaneously choose to carry the fetus to term and not, at the very least,

reduce the fetus's chances of contracting HIV constitutes a case of harm to others. As has been argued persuasively by various authors from different philosophical traditions, choosing deliberately not to act to prevent harm when one could have acted without unreasonably high costs to oneself is comparable to similarly deliberate actions that actively produce the same amount of harm.^{27,28}

What is significant about both the conservative and the liberal view is that they lead to a conclusion many would consider counterintuitive, namely that pregnant women in countries with high HIV prevalence rates should undergo compulsory testing and, if HIV positive, they should possibly be compelled to take medication to reduce the risk of perinatal transmission. The conservative, or anti-choice view, arrives at this conclusion because it prioritizes the developing fetus above women's rights to privacy and control over their own bodies. The liberal, or pro-choice view, reaches the same conclusion through a very different route. Here the argument focuses entirely on the harm-to-others case. Abortion is considered morally neutral (or nearly neutral) for reasons that predominantly have to do with the developmental state of the fetus. This pro-choice rationale leads to a seemingly nonliberal conclusion whenever women decide autonomously to carry the fetus to term. In that case, all other things being equal, there is a high likelihood that a newborn will be born. Infected newborns, then, have been harmed by their mother's refusal to test for HIV and to take the necessary medication to reduce the likelihood of passing on the infection.

DEFENDING CONDITIONALITY

Are the conditions we proposed at the beginning of our ethical and legal analysis sensible ones? We propose stringent conditions that must be met before the introduction of any mandatory testing and treatment programs. Our first condition: women must have made a voluntary decision to carry the fetus to term, and the option of abortion must be made available to them. Building on Thomson's classical analysis,²⁹ we agree that although women are not morally obliged to altruistically carry a fetus to term that they do not wish to carry to term, they are not entitled to injure or prejudice the future life of a fetus they wish to carry to term. As Colb pointed out, the latter is a qualitatively different proposition altogether.³⁰ However, if women are unable to access a reasonable alternative to carrying the fetus to term (i.e. abortion) and their decision to continue the pregnancy is rendered involuntary, it is less clear why they should accept obligations toward the fetus or the prospective newborn for that matter.

In cases in which women visit antenatal clinics too late to have an abortion (after the fetus is viable outside the pregnant woman's body in its own right), arguable that mandatory testing and treatment are acceptable. Prior to viability, abortion, from a liberal perspective, could be argued to be morally cost neutral. After viability has been attained by the fetus, destroying it is morally questionable because its survival does not depend any longer on a pregnant woman's altruistic act of carrying it to term.

Our second essential condition is that women be provided with continuing access to essential life-extending AIDS drugs. This access would have to be voluntary, in that continuing mandatory HAART treatment would not be feasible in a coercive regulatory environment. There are several good reasons for this condition. Newborns' chances of survival are improved significantly if there is a parent available to care for them. Developing countries with high HIV prevalence rates are unable to cope with the existing number of AIDS orphans. Adding orphans to those already in existence is likely to increase the strain on such societies.

Third, women who are temporarily on HAART and then taken off such medication are likely to develop drug-resistant strains of HIV.³¹ Approximately 25% of women who only have taken a HAART short course (e.g., nevirapine) develop drug-resistant HIV strains within a year. Should they give birth in a subsequent year, treatment would be substantially more difficult. They are likely to die faster as a consequence of this problem. To expect such excessive altruism from them is unreasonable. It is also likely that some of these women would introduce drug-resistant strains of the virus into the wider community, making the fight against AIDS even more difficult to win.

Our final condition is that women's confidentiality should be maintained. Although there is some evidence that the concern displayed by many pregnant women about the probable negative reaction a positive test result would trigger from partners and their communities is exaggerated, there is also sufficient evidence

to suggest that such concerns are legitimate and must be taken seriously. We propose a compromise solution. Health care providers should develop treatment strategies that enable practitioners to maintain the confidentiality of both the mother and the newborn. However, at the same time, we recognize that once women decide to carry on with their pregnancy, they must accept some of the negative consequences that flow from an HIV-positive test result, especially the difficulty of obtaining medical care for themselves and their newborns under conditions of strict confidentiality.

One could argue that, as opposed to advocating mandatory testing and treatment, we should aim to increase the number of women who voluntarily undergo testing and treatment. We should expand educational programs and persuade rather than force pregnant women to be tested and treated. We believe that although such programs are valuable, it is not good public health policy, given resource constraints in countries with high HIV prevalence rates, to divert resources away from testing and treating people toward activities related to health promotion and counseling. In cases of conflicting needs and limited resources, preserving lives must take priority over counseling.

Our analysis cannot be extended directly to developed countries with low HIV prevalence rates. The ethical framework driving our model is consequentialist in nature. The negative effect of subjecting excessively large numbers of pregnant women at very low or low levels of risk to the stress of HIV testing arguably outweighs the beneficial effect of reducing the

number of HIV-infected newborns by very few.

CONCLUSIONS

A strong prima facie case for the introduction of mandatory HIV testing of pregnant women, as well as for compulsory treatment of HIV-positive pregnant women, can be made. There remain concerns regarding the protection of women's privacy and their risk of becoming victims of various forms of stigmatization. Careful consideration of the issue leads us to propose pilot studies introducing mandatory testing and treatment programs at a number of sites in Botswana and South Africa, with a view toward establishing how such programs can best be implemented and a view toward investigating stigmatization as it affects women giving birth within these programs. Such pilot programs should also enable us to answer the question of whether or not mandatory testing and treatment would have a deterrent effect sufficiently high enough to cancel out any public health benefits that could be derived.³²

We are not suggesting that this strategy is a panacea for the continuing pandemic of perinatally transmitted HIV, given the lack of access to antenatal care faced by many women who reside in developing world countries.³³ However, whenever feasible, governments and other health care providers should consider mandatory testing and treatment regimes. ■

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Contributors

U. Schuklenk conceptualized the article, devised the structure, and developed the ethical arguments. A. Kleinsmidt wrote the sections on legal analysis and testing regimens. Both authors reviewed the article for critical intellectual content.

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