GOVERNMENT COERCION OF HIV-POSITIVE WOMEN

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March 16, 1999

FORCED TREATMENT

In the United States, several state governments have acted to override parents’ decisions, and insisted that the infants of HIV-positive mothers must be subjected to treatments with various forms of antiretroviral therapy, and some have refused to allow the newborn infants to be breastfed. Why? Are these sorts of action by government warranted?

In Los Angeles, a woman diagnosed as HIV-positive was confronted by social workers from the Child and Family Services agency because she was breastfeeding her child. They told her to go with them and have herself and her baby tested, or they would take the baby. She went with them. On the way to the testing site the officials stopped to buy infant formula, and demanded that the woman stop breastfeeding immediately (Farber, "HIV and …").

In Bangor, Maine, the mother of a four-year old boy who was diagnosed as HIV-positive refused antiretroviral therapy for the boy, partly because she had a three-year old daughter who died under comparable treatment. The state sought custody of the boy so he could receive treatment. The court denied the petition, and the state then appealed the matter to the Maine Supreme Judicial Court, where the denial was reaffirmed.

In Eugene, Oregon, the state took legal custody of the newborn son of an HIV-positive mother because she wanted to breastfeed the child and not give him AZT treatments. The state allowed the parents to have physical (not legal) custody on the condition that the infant would be given AZT treatments every six hours for six weeks, and was not breastfed.

Cases of this sort raise profound questions about the human rights of children. Under what conditions may they be forced, either directly or through their mothers, by governments to undergo particular health care treatments? Under what conditions may they be forcibly deprived of particular kinds of treatment?

The prevailing doctrine is that under normal conditions decisions regarding the care of children should be left to their parents or other legal guardians. The state may sometimes intervene, but only under extreme conditions. The major condition under which the state may intervene and override the decisions of parents is when there is clear evidence that the action proposed by the parents would seriously endanger the child. The state may intervene if, say, parents proposed to treat their child’s upset stomach with cyanide. However, the state may not intervene simply because the parents are not
following what the state deems to be optimum child-rearing practices. Similarly, the state may not intervene when there is no clear consensus regarding the effectiveness and risks of the proposed treatment. For example, if parents wanted to treat their child with some obscure herbal remedy, it would have no basis for interfering with that decision unless it had clear and strong evidence that the proposed remedy was extremely dangerous. Under most conditions, however, the parents’ freedom to make their own choices regarding the care of the child must be respected—even if they sometimes make unwise choices.

**OFFICIAL RECOMMENDATIONS**

Recommendations for dealing with pregnant women who are HIV-positive have been developed at the highest level by the United States government.

In 1993, the specialists said, “Routine antiretroviral therapy for infected children who were asymptomatic or had only minimal symptoms . . . was not recommended (CDC 1998a, p. 1)”.

In 1994 another group of top specialists advocated a program of treatment described as ACTG (AIDS Clinical Trial Groups) Protocol 076. It was tested in Thailand with a group of women diagnosed as HIV-positive. They were given AZT during their pregnancies, and their infants were given AZT, in the form of syrup, for six weeks after delivery. In the trial, all mothers used infant formula that they were provided at no cost; they did not breastfeed. This experiment was said to reduce the rate of transmission of HIV from mothers to children by two-thirds. The recommended treatment followed the same pattern.

Several observations need to be made.

1. The recommended treatment was based on a single research trial, with no replications in other circumstances.

2. The recommended treatment called for no breastfeeding, despite the fact that the trial provided no information at all on the advantages or disadvantages of breastfeeding by HIV-positive mothers. The trial assessed only maternal-fetal transmission.

3. No explanation was offered for administering AZT to newborn infants who were not breastfeeding.

4. ACTG 076 has been praised repeatedly in the literature for reducing mother-to-child transmission of the virus by two-thirds. In fact, the Thai study claimed a reduction in transmission from a rate of 25.5% to 8.3%. This is a reduction of 17.2%, not 67%. It is misleading to refer to the ratio of the two percentage figures, rather than the difference between them. If comparison of percentages (or ratios) were used, then a reduction from, say 0.002% to
0.001% could be described as a 50% reduction, which is absurd and misleading.

(5) The health benefits for the infant were simply inferred on the basis of blood tests. No assessments were made of the actual health outcomes for the infants. The report acknowledged that “the long-term risks for the child associated with exposure to ZDV in utero and early infancy have not been determined (CDC 1994, p. 4, also pp. 5, 6).” Potential long-term toxicity was acknowledged. Not only the risks, but also the health benefits were not determined.

(6) The recommendations stated: “Discussion of treatment options should be noncoercive, and the final decision to accept or reject ZDV treatment recommended for herself and her child is the right and responsibility of the woman. A decision not to accept treatment should not result in punitive action . . . (CDC 1994, p. 7).”

There were no grounds for coercive action set out in the 1993 or 1994 recommendations. Was there something in later recommendations?

Recommendations issued in July 1995 again were based on the single trial of ACTG 076. Again, it was acknowledged that the long-term safety of the treatment for both mothers and infants was unknown. It was also reaffirmed that “Discussions of treatment options should be noncoercive—the final decision to accept or reject ZDV treatment is the responsibility of the woman (CDC 1995, p. 4).”

New U.S. Government recommendations released in April 1998 once again were based on ACTG 076. These 1998 guidelines acknowledged that “Data from clinical trials that address the effectiveness of antiretroviral therapy in asymptomatic infants and children with normal immune function are not available (CDC 1998a, p. 15).” Moreover, “The theoretical problems with early therapy include the potential for short- and long-term adverse effects—particularly for drugs being administered to infants aged <6 months, for whom information on pharmacokinetics, drug dosing, and safety is limited (CDC, 1998, pp. 15-16).” Even for infants who are claimed to be infected, “clinical trial data documenting therapeutic benefit from this approach [antiretroviral therapy] are not available (CDC 1998a, p. 17).”

On March 1, 1999 the U.S. Government published still another set of “Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection”, based on new research and the availability of new drugs. However, it was acknowledged that there were still no data available on the effectiveness of antiretroviral therapy in asymptomatic infants with normal immune function (p. 11).

In the Oregon case the newborn infant weighed 7 lbs., 7 oz., and appeared to be perfectly healthy. He showed no symptoms, and was not claimed to be infected. The 1998 and 1999 guidelines do not recommend antiretroviral treatment for infants who are not
infected or who are claimed to be infected but show no symptoms. Nevertheless, the State of Oregon took custody of the infant, and the parents were charged with “intent to harm” the child.

A major publication on Pregnancy and HIV: Is AZT the Right Choice for Your Baby? distributed by the United States Public Health Service was drawn from a U.S. Government-sponsored publication entitled You, Your Baby, and AZT: The Choice Is Yours. (It can be accessed via the Worldwide Web at http://www.hivatis.org/pregnhiv/azttoc.htm) The USPHS publication was illustrated with the following drawing:

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“I talked to my doctor about AZT. Now the decision is mine.”
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The government’s policy in support of free choice is evident in these publications’ titles and in this drawing’s caption.

ISSUES

There are many who argue that AIDS is not well defined, question whether HIV causes AIDS, and question whether HIV really exists. All tests for identifying HIV status have been seriously challenged. Questions have been raised about whether the virus really can be transmitted via breastfeeding. However, even if we accept that the virus exists and that it can be transmitted through breastfeeding, there are still many reasons to question whether breastfeeding by HIV-positive mothers is in fact lethally dangerous.

It should be recognized that:

1) The probability of transmission of HIV via breastfeeding is not clearly known. Estimates vary widely.

2) There is no good way to assess the HIV status of a newborn infant.

3) Where infants are diagnosed as having HIV, the long-term implications for their health have not been clearly assessed.
4) The long-term health benefits and risks of antiretroviral drug treatment for infants have not been scientifically established.

5) There is substantial risk of negative effects of antiretroviral drug treatment.

6) Formula feeding is inferior to breastfeeding.

7) Taking the child away from its parents deprives the child of its proper care.

8) Forcing specific treatments is contrary to clear and direct federal recommendations against coercive action.

9) If HIV-positive mothers are to be stopped from breastfeeding, they should be offered and informed about a full range of alternatives, and not just formula. These alternatives should include options based on human milk, such as (a) expressing and heat-treating one’s own milk, (b) using milk from a quality-controlled milk bank, and (c) using a carefully selected wetnurse.

10) If HIV-positive women and their infants are to be coerced to follow particular courses of treatment, there must be a clear and explicit legal basis for it, and all comparable cases must be treated in the same way.

11) There is an obligation for the government to clearly explain to affected families the legal and medical foundations for coercive health care treatment.

12) A policy of coercive treatment of women who have been diagnosed as HIV-positive could lead some women to refuse to be tested.

JUSTIFICATION FOR GOVERNMENT INTERVENTION

Should government intervene whenever an individual makes a judgment that is less than optimal in the government’s view? Is it the government’s job to protect us from all risk? Then why does it allow smoking? Why does it allow people to eat junk food? In the United States, the number of perinatally acquired AIDS cases has never reached as high as a thousand in a single year (CDC 1997, p. 1089). According to one CDC report, in 1997 there were only 473 children with AIDS (CDC 1998b, p. 2). According to the HIV/AIDS Surveillance Report there were an estimated 299 new cases of pediatric AIDS diagnosed in 1997 (CDC 1998c, p. 33). Not all of the infants diagnosed with AIDS die early. Yet, in 1997 car crashes killed 1,627 children. Clearly, the risk of children dying in cars is far greater than the risk resulting from HIV infection or from AIDS. Why does the government allow us to put children into cars?

In ordinary circumstances, governments should leave us to our own devices, making our own decisions, even if that means we may occasionally make decisions that look foolish to others. Government intervention is warranted only in extraordinary situations. Governments may justifiably block individuals from making decisions in
which their decision is certain to lead to an extremely bad outcome, such as death or severe injury. Most of us would agree that a mother about to treat her child’s stomachache with cyanide should be stopped.

In the case of HIV-positive mothers, however, it has not been clearly demonstrated that breastfeeding would be extremely and definitely harmful to the health of the infant. Sampling of all the relevant literature (and not just selected portions of it) clearly demonstrates that the experts are divided on the question. Similarly, it has not been unambiguously demonstrated that antiretroviral treatment of HIV-positive mothers and their infants would improve their health outcomes. The experts are divided.

Health care practitioners are expected to advise their clients regarding the choice of treatment. When governments consider compelling particular treatments, they must be held to much higher standards than health care practitioners who merely advise. If there is be any form of compulsion, the information must be decisive. The question is not simply whether breastfeeding might be somewhat better or worse than not breastfeeding, or whether AZT might be somewhat more beneficial than harmful. Compulsion is warranted only if there is unambiguous scientific evidence that the treatment being contemplated would, with virtual certainty, result in extremely serious harm. Governments simply do not have information of that kind in relation to the likely effects of breastfeeding or antiretroviral treatment for the infants of HIV-positive women.

Coercive medical treatment may sometimes be warranted in extraordinary cases, but the burden of proof is on the state to show that there are compelling reasons for it. There is as yet no adequate scientific or policy basis to justify governments’ forcing the use of antiretroviral drug treatments or preventing breastfeeding by HIV-positive women.
BIBLIOGRAPHY


