

THE TYSONS' MISSING TESTIMONY

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On September 17, 1998, Kathleen Tyson of Eugene, Oregon, then six months pregnant, was told that her blood tests indicated that she was HIV-positive. Her son, Felix, was born on December 7, 1998. He appeared to be healthy in every way. Less than 24 hours after his birth, Kathleen was pressed by a pediatrician to treat Felix with AZT, an antiretroviral drug, and to not breastfeed him. Having studied the issue along with her husband, David, she declined to accept that advice. Within hours, a petitioner from Juvenile Court came to her room, and issued a summons for her to appear in court two days later. She and her husband were initially charged with "intent to harm" the baby, but the petition, dated December 10, 1998, said that the child "has been subjected to threat of harm." When the Tysons appeared in court, they were ordered to begin administering AZT to Felix every six hours for six weeks, and to stop breastfeeding completely. The court took legal custody of the infant, but allowed the Tysons to retain physical custody so long as they obeyed the court's orders (Tyson).

A trial was held in Eugene, Oregon from April 16 to April 20, 1999. The Tysons lost, so the state retained legal custody of Felix. The Tysons continued their physical custody, and agreed that, as ordered, he would not be breastfed.

I coordinate a Task Force on Children's Nutrition Rights, serving both the World Alliance on Nutrition and Human Rights and the World Alliance for Breastfeeding Action. I have also written a good deal about the human right to food and nutrition, and I was an invited participant in two Expert Consultations on the Right to Food organized by the United Nations. I am a member of the Working Group on Nutrition, Ethics, and Human Rights of the United Nations' Administrative Committee on Coordination/Sub-Committee on Nutrition. An unpublished study of mine on *HIV/AIDS and the Nutrition Rights of Infants* has circulated widely, and a summary version has been published in *Mothering* magazine (Kent). On this basis I was asked to serve as an expert witness for the Tysons.

When my turn came up at the trial, I was sworn in, and the Tysons' lawyer, Hilary Billings, asked me to review my background. Then Billings explained that he was going to ask me to speak about the human rights dimensions of the case, especially in regard to the issue of government coercion. At that moment the judge intervened, and said these matters were irrelevant. I then had to step down.

Having been unable to present my views in court, I am presenting them here.

By the time of the trial in April 1999, Felix had already completed his six weeks of drug treatment. Therefore the court case dealt only with the remaining legal issue, whether he could be breastfed. So far Felix has been diagnosed as HIV-negative.

However, if he were to be diagnosed as HIV-positive in the future, the state might insist that AZT treatments should be resumed. Thus, because of the past and possible future government coercion regarding drug treatment, I will discuss the issues relating to drug treatment as well as to breastfeeding.

FORCED TREATMENT

The Tysons' case is not the first of its kind in the United States. 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.

Thus, 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. Some have refused to allow the newborn infants to be breastfed. Why? Are these sorts of action by government warranted? These cases raise profound questions about the human rights of children and their parents. 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. As I understand it, 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. Coercion by government is warranted only if there is compelling evidence of a high risk of extreme harm.

Are these conditions met when mothers are diagnosed as HIV-positive? The relevant United Nations agencies and the United States federal government have taken a clear stance on the issue.

OFFICIAL RECOMMENDATIONS

At a United Nations Technical Consultation on HIV and Infant Feeding held in Geneva in April 1998, David Clark, Legal Counsel for UNICEF in New York, described the basic human rights principles relevant in the situation of mother-to-child transmission of HIV/AIDS. First among these is . . .

the right to life, and the highest attainable standard of physical and mental health; in the case of children breastfeeding is an important component of the right to health, however, only the mother can decide whether to breastfeed her child or not (WHO 1998a, p. 19).

In the discussion it was reaffirmed that “In all cases, the HIV-positive mother’s own needs and wishes should have priority (WHO 1998a, p. 35).” The consultation reached a “broad consensus on a public health approach based on universally recognized human rights standards,” and in that consensus the UN agencies recognized that:

HIV-positive mothers should be enabled to make fully informed decisions about the best way to feed their infants in their particular circumstances (WHO 1998a, p. 8).

The view that it is the mother’s right to decide how she will feed her child was reaffirmed by the major international agencies in manuals on HIV and infant feeding release in June 1998 (WHO 1998b, p. 6).

In the United States, recommendations for health care workers dealing with pregnant women who are HIV-positive have been developed at the highest level by the federal government.

In 1994 a group of top U.S. specialists advocated a program of treatment described as ACTG (AIDS Clinical Trial Groups) Protocol 076. Their 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).”

Recommendations issued in July 1995 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).”

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*. The USPHS publication was illustrated with the following drawing:



***"I talked to my doctor
about AZT. Now the
decision is mine."***

The federal 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. The Dunn study, cited frequently in the Tysons' court proceedings as the basis for claiming that there is a 14 percent chance of transmission of the virus through breastfeeding, is seriously flawed, and of questionable relevance to the Tysons' situation. The state's experts in the court proceedings appeared to be unaware of a thorough study of vertical transmission in the United States by Stoto and colleagues, published by the National Academy of Sciences (Stoto). That study indicates that the transmission rate via breastfeeding is at most 1.65 percent in the United States. In its recommendations for action, this study did not voice any concern at all about breastfeeding.
- 2) There is no good way to assess the HIV status of a newborn infant. Where infants are diagnosed as having HIV, the long-term implications for their health have not been clearly assessed and reported in the scientific literature.
- 3) More importantly, the health impacts of different feeding methods by HIV-positive mothers have not been assessed and compared in any well-designed studies in the literature. As the United Nations agencies acknowledge, "currently

there is little information regarding the effect of replacement feeding on infant morbidity and mortality for infants whose mothers are HIV-infected (WHO 1998c, p. 13; also p. 17).” I had come to Eugene from a high level United Nations meeting in Geneva on nutrition. At that meeting I asked experts from the major United Nations agencies whether they had information on the likely health impacts of different feeding methods by HIV-positive mothers, and they acknowledged that they did not.

- 4) The long-term health benefits of antiretroviral drug treatment for infants have not been scientifically established. Furthermore, no explanation has been offered for the administration of such drugs to an HIV-negative, asymptomatic infant who is not breastfeeding. There is substantial risk of negative effects of antiretroviral drug treatment.

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

Recommendations issued in July 1995 acknowledged that the long-term safety of antiretroviral treatment for both mothers and infants was unknown (CDC 1995).

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 United States 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 (CDC 1999, p. 11).

At birth Felix weighed 7 lbs., 7 oz., and appeared to be perfectly healthy. He showed no symptoms, and was not claimed to be infected. The CDC’s 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.

- 5) Formula feeding is inferior to breastfeeding. There could be an exception to this rule in the case of infants of HIV-positive mothers, but evidence to demonstrate this has not yet been published. There are some early indications that breastfeeding may actually provide protection against HIV infection.
- 6) Forcing specific treatments is contrary to clear and direct recommendations against coercive action from both United Nations agencies and the United States federal government.
- 7) 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.
- 8) 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. There are many HIV-positive mothers who breastfeed their infants.
- 9) There is an obligation for the government to clearly explain to affected families the legal and medical foundations for coercive health care treatment.
- 10) 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

In my view, 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.

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.

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) 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.

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 to 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 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 on the infants of HIV-positive women.

If coercive medical treatment is required by the state, 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.

Surely the physicians who took the state's side in the case against the Tysons' sincerely believed that the Tysons were endangering Felix. However, the scientific community has failed to meet its obligations to produce the strong and clear scientific knowledge that is needed to guide individuals in situations like that faced by the Tysons. I believe that if the Tysons had been presented with clear, hard evidence that breastfeeding Felix would be likely to harm him, they would have decided accordingly. We have clear indications of the physicians' strong beliefs, but we do not have hard, scientifically sound studies of the sort they themselves claim to require. If there is a failure of informed consent, there is an obligation on the part of government and health care workers to provide better information. Resort to coercion is not the appropriate remedy.

The issues in the Tyson case go beyond the question of what would be the most appropriate health advice in these specific circumstances. There are also serious issues of public policy, government coercion, and human rights, issues that are beyond the recognized competence of those who are trained in medicine. Soon after the Tyson trial ended, I was told by an angry physician who testified in behalf of the state that I should not pretend to be an expert in areas in which I am not an expert. I was reminded that I am not a physician. I think there are issues here that go beyond the bounds of medicine.

The judge in this case indicated that he was only interested in Oregon state law, and was not concerned with policy at the United Nations level or at the federal government level. While he was not legally obligated to follow recommendations from these sources, or to adopt their perspectives, surely something can be learned from them. The coercion of individuals who have been diagnosed to be HIV-positive has become a

worldwide epidemic. The issue requires judgments that are fully informed not only by sound medical research but also by careful analysis of the human rights issues at stake.

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