

2. AIDS and Reproductive Decisions: Having Children in Fear and Trembling

JOHN D. ARRAS

Albert Einstein College of Medicine—Montefiore Medical Center

THE AIDS EPIDEMIC POSES PAINFUL MORAL DILEMMAS for both HIV-positive women and their health-care providers. For the women, the decision to reproduce, normally a decision charged with love and hope for the future, is now tainted with the prospect of infecting one's own child with a painful and lethal disease. The gift of life may well yield a sentence of death. Ought such women to forgo childbearing for the sake of children who would have been born infected? If already pregnant, should they abort "for the sake of the fetus"?

For health-care providers and counselors the problem is how to advise such women. Is it ethical to counsel them to avoid conception or, if pregnant, to abort? Would such a departure from traditional non-directive counseling norms be consistent with respect for women's reproductive rights? Would it be effective in changing behavior?

These questions tend to elicit passionate yet contradictory responses from diverse sectors of our society. On the one hand, federal and state health officials and a significant portion of the population tend to view the problem in terms of the overall *public* objective of reducing the spread of a lethal virus to the offspring of HIV-infected women. Given the catastrophic nature of the illness and the high risk of its perinatal

transmission, many people wonder how anyone could possibly intend to have a child under such circumstances. They are appalled and mystified by reports of HIV-infected women who become pregnant again after watching their first child die of AIDS. From their perspective, the decision to reproduce under the specter of AIDS is a paradigmatic example of parental irresponsibility.

On the other hand, many AIDS counselors and activists, advocates of reproductive rights, and infected women insist that the choice to bear children or not is a quintessentially *private* choice for the woman. They note that infected women have a fundamental, constitutionally protected right to make such decisions, and that, whereas many others might differ with their conclusions, these women can and do make responsible decisions based upon their own cultural, social, and economic conditions. Recalling the past abuses of genetic counseling in minority communities, these voices condemn directive counseling as a presumptuous, selective, and possibly racist assault on the reproductive rights of a highly vulnerable population.

This article draws on both sides of the debate and attempts a fusion of these opposed perspectives. I shall argue that although the risk of perinatal HIV transmission is not presently a sufficient warrant for morally criticizing any particular woman's choice, and although many women's decisions to have children may be eminently justifiable, a contextualized assessment of several morally relevant variables might nonetheless justify judgments of reproductive irresponsibility in some cases. Should the future development of a reliable prenatal diagnostic test make some infected women's choices clearly unacceptable according to the societal consensus on acceptable risk, I argue that society *would* be justified, absent corresponding breakthroughs in AIDS treatment, in articulating and encouraging compliance with a normative standard of responsible reproduction.

The final section of the article probes the implications of these ethical conclusions for possible societal interventions on the reproductive choices of HIV-infected women. Rejecting any and all forms of coercive actions, threats, or pressures, I call for a "moral education" model of nondirective counseling for most HIV-infected women. Under some rigidly defined circumstances, however, I argue that even a version of directive counseling might be morally permissible now for some clearly irresponsible decisions and, in the future, for all infected women designated by a reliable prenatal diagnostic test.

The Medical and Social Context

The Faces of Pediatric AIDS

The epidemiological dimensions of pediatric AIDS are alarming. As of April 1990, the Centers for Disease Control (CDC) has reported approximately 1,800 cases of perinatally transmitted pediatric AIDS, and it is reasonable to assume that three to four times that number are HIV infected (Centers for Disease Control 1990). In those urban neighborhoods most seriously affected by intravenous drug use, the percentage of infected women delivering children reaches as high as 4 or 5 percent (Novick et al. 1989). Nationally, 1.5 women out of every 1,000 delivering a child are infected, which yields a total of approximately 5,900 births to infected mothers per year (Gwinn 1990). Although the exact dimensions of the pediatric epidemic are hard to gauge, we can expect the number of newly infected children to rise steadily over the next several years as the focus of the larger epidemic shifts to drug addicts and their sexual partners in the inner cities.

Much medical uncertainty derives from our inability to detect HIV infection in utero or before the child's first year of life. Virtually all children of HIV-positive women will be born with antibodies to the AIDS virus, but most of these will not actually be infected. Their so-called "passive" antibodies come from the mothers' blood and usually disappear after one year (Falloon, et al. 1989). Current studies indicate that the risk of actual perinatal HIV infection through any given pregnancy lies somewhere between 20 percent and 30 percent (Andiman et al. 1990; Falloon et al. 1989; Ryder and Hassig 1988).

Our current inability to predict which pregnancies will result in the vertical transmission of the AIDS virus may, however, be remedied in the near future. A number of researchers have already reported promising leads that might, within two years, yield a prenatal test with a high degree of reliability. Preliminary studies indicate that children born to mothers with antibodies to the glycoprotein gp120 may have a higher likelihood (e.g., 85 to 90 percent) of being negative, whereas the absence of such antibodies might predict the presence of infection (Rossi et al. 1989; Devash et al. 1990; Goedert et al. 1990). Although such a maternal blood test would not allow the same degree of confidence available in prenatal tests for disorders like Down's syndrome or Tay-Sachs disease, it would vastly improve our prognostic capacities and significantly alter the moral equation.

What is the long-term clinical outlook for children infected with HIV? This question is complicated by a wide spectrum of clinical manifestations. The most severely afflicted children present with adult-style opportunistic infections, such as *Pneumocystis carinii* pneumonia (PCP), during the first year of life. Constituting nearly one-fourth of all infected children in some clinics, these children tend to do extremely poorly, usually dying painful deaths within a month or two after diagnosis. Other infected children have far milder manifestations, such as bacterial infections, are diagnosed at a later date, and live much longer (Scott 1989).

The aggregate median survival time for infected children in one recent study was 38 months from the time of diagnosis (Scott 1989). The death toll of HIV infection is highest in the first year, with rates in the range of 17 to 25 percent. After that, we can expect the progressively deteriorating immunological status of most HIV-infected children to lead eventually, although perhaps over a period of several years, to severe opportunistic infections and death. Thus, assuming no dramatic breakthroughs in antiviral therapy over the next few years, we can predict that approximately 25 to 30 percent of all infected children will die before two years; 50 percent may die before their seventh birthday; and most of the remainder will face the constant threat of premature death from inevitable opportunistic infections.

Such estimates of prognosis and mortality are a moving target, however, due to the recent availability of drugs like zidovudine (AZT), prophylactic agents against opportunistic infections, and the promise of even more effective drugs in the near future. Despite some serious side effects, many clinicians report benefits from AZT therapy in children, both in terms of length and quality of life (Pizzo 1989; Warren Andiman 1990, personal communication). However, it is still too early to tell whether such treatments will only *delay* the inevitable for a year or more, as appears to be the case with most adults. Still, the advent of effective early intervention against HIV infection in children holds out the possibility of transforming HIV infection from a nearly uniformly fatal illness into a chronic, yet extremely burdensome, disease.

The Social Context

In contrast to most genetic diseases, the diagnosis of AIDS in a child usually signals an entire family at risk—a “dying family” (Septimus 1989). By the time the diagnosis is made, the father is often already

sick or dead and the mother must cope not only with an afflicted child, but also with the dread of her own approaching symptoms and death. Many parents are too ill to take responsibility for the care of their own children, both infected and normal, who are often abandoned in hospitals or handed over to foster care (Gross 1987).

With the exception of spouses of HIV-infected hemophiliacs—who, as of April 1990, have given birth to 113 infected babies (Centers for Disease Control 1990)—the mothers of these children tend to be poor and members of minority groups. They become infected either through intravenous drug use or heterosexual contact with infected drug users or bisexual men.

In spite of the seriousness of the risk of perinatal transmission to their offspring, HIV infection and its accompanying moral dilemmas are often far down on the list of immediate concerns occupying these women. Typically, women at risk of HIV infection are also subjected to all the shocks and ills of life in urban ghettos: poverty, chronic unemployment, poor or nonexistent education, substandard housing, crime, drug abuse, spousal abuse, and the lack of medical and social supports. What to do about HIV infection is thus often perceived as just one more problem within an unrelentingly grim horizon. (See “Uncertain Risks and Bitter Realities” by Carol Levine and Nancy N. Dubler in this issue.)

Finally, infected women belong to subcultures that view childbearing as an often unique source of female self-esteem and social respect (Gross 1987; Holman et al. 1989). Although women from these subcultures cannot be said to value children more than other women, alternative sources of respect and gratification (e.g., education, enjoyable work, public service, or raising adopted children) are effectively closed off to them. Thus, whereas middle-class women might consider comparable risks of a bad outcome to be prohibitive, most HIV-infected women do not opt for abortion (Selwyn et al. 1989).

Neglected Issues

Access to Health Care and Reproductive Services

Although the problems addressed in this article are pressing and important, they are not the only, or even the major ethical problems con-

cerning women at risk for the perinatal transmission of AIDS. Although the issues of reproductive choice and appropriate counseling are perhaps most amenable to an individualistic focus and spirited ethical debate, problems of social justice and access to services are of paramount ethical importance as we enter the second decade of the AIDS epidemic. In contrast to their middle-class critics, who would have them exercise greater reproductive responsibility, the women we are talking about suffer daily from intense social discrimination and lack of access to the most basic levels of prenatal and primary medical care, effective drug rehabilitation, sex education, and abortion services.

In the context of such pervasive injustice and deprivation, an *exclusive* concern to limit the reproductive activity of HIV-infected women is both short sighted and hypocritical. Professions of concern for the offspring of HIV-infected women would ring truer if those advocating more reproductive responsibility also called for some long-overdue *social* responsibility toward the needs of poor women of color (see Levine and Dubler in this issue). Honoring the terms of the social contract with these women through economic, social, medical, and educational opportunities would do much to augment their decision-making capacities.

Indeed, lack of access to the health-care system is directly related to the outcome of women's reproductive decisions. In stark contrast to middle-class women, HIV-infected pregnant women rarely make early contact with the health-care system. One study of 49 medical centers by researchers at the National Institutes of Health found, for example, that only 17 percent of HIV-positive women began prenatal care during the first trimester. Of the remainder, 43 percent made their first contact during the second trimester, 22 percent during the third trimester, and 17 percent had no prenatal care at all (Stratton, Mofenson, and Willoughby 1990). Because abortion becomes much more problematic (medically, psychologically, and ethically) after the first trimester, it should come as no surprise that the reproductive decisions of these women are not significantly altered by their contacts with the health-care system. Whether or not one agrees with the controversial claim that society has no *moral right* to encourage reproductive restraint among HIV-infected women in the absence of improved access to medical and social services (see Levine and Dubler, this issue), the provision of these services early in pregnancy is obviously a necessary precondition of counseling and increased restraint.

The sad truth, however, is that even a concerted public effort to foster social justice will not eliminate the ethical questions of whether HIV-infected women should have children and how to counsel them. We are not faced with an either/or choice between social and individual responsibility. Clearly, our society must be condemned for failing to provide HIV-infected women with decent and humane medical services and more equitable social opportunities. Equally clearly, the reproductive decisions of infected women have serious and problematic ethical implications for their offspring, which require careful examination. The well-being of children should not be held hostage, even to legitimate and pressing demands for social reform.

The Responsibility of Men

An attentive witness to the public debate over AIDS and reproductive responsibility could easily conclude that men have nothing to do with either the problem or its solution. There are several plausible explanations for this exclusive focus on women's choices and the counseling of women. First, women often lack committed partners willing to share the burdens of decision making, not to mention the burdens of child rearing. They are thus often the only responsible moral agents left on the scene to engage. Second, because women have a direct physiological connection to children that men lack, educational and counseling efforts directed to them will naturally be more focused and efficient. Likewise, women in need of prenatal health care are much more likely than their young male counterparts to enter the health-care system and to be attentive to messages about the possible fate of their offspring. Finally, it should not be at all surprising that men's responsibility goes unnoticed when we consider how the case for women's reproductive freedom has been pressed so persistently and exclusively in the language of feminist liberal individualism. We are so used to being told, for example, that abortion is a "private choice" for the "woman alone" to make that it requires some effort to recall that men might yet have some legitimate role in collaborative reproductive decision making and considerable responsibility for reproductive outcomes.

Even though this article will focus on women's pivotal role in decision making and counseling, we must bear in mind throughout that a heavy burden of responsibility falls on men as well. As the primary vectors of AIDS, men at risk for HIV infection have a rigorous moral duty

both to inform their female sex partners of their status and to refrain from engaging in unprotected sexual activity that endangers both the women and their future children. Thus, public educational messages concerning “safer” sex and reproductive responsibility must also be addressed to men.

The Decision to Reproduce: Preliminary Ethical Considerations

A Moral Issue

Because our public discourse about reproduction focuses on the moral or legal *right* to make decisions, we often overlook the fact that the concrete decision about whether or not to bear a child is fraught with *moral* significance. Given that women have the right to choose, *how* should they choose?

Whatever one’s views on the moral permissibility of abortion, a newborn child is, or will soon become, a being with a separate dignity and genuine interests. Children are not the possessions of their parents or mere means to the satisfaction of parental desires (S. Callahan 1979). Once a woman decides to carry a child to term, her fetus—whatever its abstract metaphysical status—becomes a future child, who, when born, will have a serious stake in life and health. If the intentional and avoidable actions or health status of pregnant women cause predictable damage that will manifest itself in illness and disability for the children who will be born, we can legitimately criticize them for failing to respect their children’s separate dignity and entitlement to protection.

The claim that reproductive decisions should be the object of moral scrutiny is deeply troubling to many people, and for good reason. In a legal climate waxing increasingly hostile toward women’s self-determination, one need not be paranoid to interpret calls for greater reproductive responsibility as part of a repressive, patriarchal strategy to curb reproductive rights. Although there are certainly grounds for caution in this sensitive area, a salutary defensiveness about women’s rights should not preclude discussion of the moral *use* of those rights in the age of AIDS.

Here too, we are not faced with an either/or choice between individual rights on the one hand and making conscientious choices on the

other. If, as Ronald Bayer (1989) has cogently argued, the challenge posed by the AIDS crisis is the voluntary alteration of deep-seated behaviors, and if this in turn depends upon the creation of a public culture of restraint and responsibility—a culture that largely eschews coercive legal measures as both unethical and counterproductive—then we must strive to foster a public dialogue about the ethical implications of AIDS for parental responsibility. Given the alarming toll of pediatric AIDS, we must at least attempt to chart the contours of a moral culture in which the content of women's reproductive decisions might be critically discussed, while their legal right to make such decisions remains inviolate (D. Callahan 1981).

Different Choices

The ethics of deciding whether or not to reproduce crucially depends upon the means chosen to that end. The alternatives are preventing the coming-into-being of a child through contraception and sterilization or the prenatal destruction of a potential human life by means of abortion. Clearly, women can and do differ on the moral permissibility of all three methods of avoiding reproduction.

For the vast majority of women, contraception is not viewed as a morally problematic means of limiting fertility. By preventing the union of sperm and egg, most contraceptive methods do not entail the destruction of a being already in possession of its full, human genetic code. Because unconjoined gametes are not the sort of beings that have interests or a stake in things, preventing them from joining together to form a new life does them no harm and violates no one's interests (Feinberg 1984; Steinbock in press).

By contrast, sterilization and abortion pose serious psychological, moral, and political problems. Although some women might prefer sterilization as the most effective barrier to the transmission of HIV to the fetus, many others would reject it as a psychologically devastating and irrevocable solution that might subsequently be regretted in light of future medical advances. In addition, given this country's history of coercive sterilization of poor women of color, any widespread discussion of sterilization, even if completely voluntary, is bound to heat up the already charged political atmosphere with accusations of eugenics and genocide.

In contrast to artificial contraception, which hardly anyone thinks

immoral, abortion poses complex psychological and moral problems. No matter how necessary or justified, the termination of a pregnancy will usually be an occasion of sadness and a sense of loss for the woman. Furthermore, from a moral perspective, abortion is obviously a hotly contested issue. Some think abortion morally justified in most circumstances, especially to prevent the transmission of HIV; others believe that early abortions are permissible, but that late-term abortions are not; still others consider all abortion the moral equivalent of murder. Although the latter group might be urged to use contraceptives, they can hardly be expected to abandon strongly held religious beliefs about abortion. Accordingly, it should be more difficult to establish a moral duty to abort at-risk fetuses than to justify a duty to prevent conception in the first place.

Moral Elements of Reproductive Responsibility

Assessing the ethical dimensions of reproductive choices is a complex, difficult, and controversial task. We must first identify the most important elements of any ethical assessment and then attempt to weigh and balance them against one another. These elements include: (1) the ability and willingness of parents to assume their proper responsibility for the child; (2) the magnitude of the threatened harm; (3) the probability of the harm actually occurring; and (4) the burden that parents must assume in order to avert the threatened harm.

Although the list of elements is familiar, the task of weighing and comparing is complicated by the absence of clearly defined standards within each rubric (e.g., What risks are acceptable? What parental burdens are unbearable?) and by the absence of a recognized rule for ranking the relative importance of each element (e.g., What level of parental burden might compensate for a certain level of risk to the child?). At crucial points in the argument we will have to rely on interpretations of vaguely defined societal standards embedded in our responses to analogous situations. This method may not be rigorous or "objective," but it would appear to give us the only kind of evidence and assurances allowed by the subject matter.

I canvass here two distinct arguments against HIV-infected women having children, both of which primarily concern the harm/probability

ratio. The first is based narrowly upon the concept of “wrongful life”; the second is premised on the more expansive notion of high risk of serious harm. I begin, however, with some remarks on parental responsibility because this element combines with any and all arguments based upon the magnitude and probability of harm.

Parental Inability to Assume Responsibility

As Sidney Callahan (1979) justly observes, a “principle of proportionality” is applicable in reproductive ethics: the less consequential the risk, and the more one is able and willing to personally assume responsibility for bad outcomes, the more morally justified it is to assume the risk. In all too many cases, however, by the time children receive a diagnosis of HIV infection their parents are themselves already dead, manifesting severe symptoms, or incapacitated by drug use (Septimus 1989). As a result, they are often incapable of caring for the very children whom they put at risk. Although it may be morally appropriate for parents to chance having a grievously afflicted child so long as they are willing and able to take responsibility for the child—provided that the child is not placed at excessive risk of serious harm—it is much more problematic to have a severely burdened child only to leave her bereft of parental nurturing through illness, death, or drug-induced neglect. The often intense desire for children must be tempered by an acknowledgment of one’s responsibilities as a parent.

Parents have duties to their children to provide all sorts of things, including shelter, nutrition, education, and emotional nurturing. It is a good reason not to have children if a person can predict well in advance that he or she will be incapable of discharging these parental duties in the near future, and this is especially true in cases where the woman’s male partner or extended family is likewise unavailable for parenting.

If parents are unable to discharge their responsibilities, foster care and adoption are reasonable and necessary remedies. The question, however, should be whether parents ought to put themselves and their children into such a position in the first place, knowing that the risk of eventual disconnection and forfeiture of duty is high. I believe that the presence of such a risk constitutes a good reason not to have children in the first place, whether or not the children turn out to be infected.

However, this is not to say that it should in every case be a *compelling* reason for reproductive restraint; other factors might singly or in combination outweigh it in any given instance. Nevertheless, it is an important factor to be weighed in every case.

The Harm/Probability Ratio

In general, the greater the magnitude and probability of predicted harm, the less justifiable it is to have children. In spite of its apparent simplicity, this articulation of the “harm principle” invites controversy. A harm that some might view as excessive, others might consider an acceptable price to pay for a desired end. A level of risk that some find prohibitive might be quite tolerable to others accustomed to a different social milieu (Rescher 1983). Notwithstanding this sort of controversy at the margins, paradigmatic examples of responsible and irresponsible reproductive behavior do exist and might provide a reasonably secure foundation for judgments about the choices of many HIV-infected women.

We shall shortly examine two distinct arguments for reproductive restraint based upon the harm principle. First, however, I want to make an important distinction between taking risks for oneself and for others. When an act is “self-regarding,” in the sense that its primary consequences fall on the individual agent herself, we are rightly quite willing as a society to grant the individual very wide latitude in identifying and evaluating risky behaviors. As Mill put it, when purely personal conduct is at stake, a meddling society will usually intervene wrongly and in the wrong place (Mill 1859).

When an act is “other regarding,” however—that is, when it has potentially harmful consequences for other persons—our attitude should be much more conservative. Behavior of this sort requires a far stronger moral justification than potentially self-destructive actions (Rescher 1983). It will not do, then, merely to ask what level of risk HIV-infected women are willing to run on their own behalf. Instead, we must attempt to determine the level of risk to which they may justifiably expose other persons.

The Claim of “Wrongful Life.” By far the most powerful argument against HIV-infected women having children would be that such a choice places future offspring at unacceptable risk of catastrophic harm. By this, I mean harms so great that no one would want to live such a

life. In contrast to the usual sort of case where already existing persons are said to suffer harm, in these worst cases to be born in such a terrible condition is itself said to constitute a harm to the child and a violation of his or her right to be born with at least a chance for a minimally decent life—hence the legal term, “wrongful life” (Feinberg 1984).

According to this account, a child suffers the harm of wrongful life if it would be rational for a proxy chooser—that is, a representative of his or her “best interests”—to prefer nonexistence to the child’s ever having been born. In other words, a “reasonable person” concerned about the child’s welfare would conclude that, if all of his or her important interests, no matter what they are or might come to be, are doomed from the very start, it would be irrational to prefer the birth of such a child to nonexistence (Feinberg 1988).

Equipped with an appropriately conservative attitude toward risk, a proponent of the wrongful-life argument would then hold that a 20 to 30 percent chance of exposing another person to HIV infection is quite simply too high. He might ask us to imagine society’s response if thousands of children with Tay-Sachs disease were born each year to known carriers who neglected to seek amniocentesis and abort afflicted fetuses. Such a widespread practice of exposing one of every four children to a wrongful life would clearly violate our societal norms of responsible reproductive risk.

Although I think that the wrongful-life argument is valid in theory, its deployment in the present context is highly problematic. In order for the argument to succeed here, it must be shown that all (or at least the vast majority) of infected children will have lives so brief and so filled with suffering that they qualify as “wrongful.” But given the bimodal manifestation of HIV infection in children, this will be extremely hard to show. Only a relatively small percentage (say, 10 to 20 percent) of those born HIV infected actually fit the worst-case scenario of early infection, chronic hospitalization, and death before the age of two. The rest will develop different and often less lethal manifestations of AIDS later on and will live longer, perhaps to the age of ten or beyond. The longer these children live with a tolerable quality of life, the more their lives will be worth living. A child who lives at home, goes to school, and attends summer camp does not fall into the same category as a Tay-Sachs baby.

The consequence of this for the wrongful-life argument is that we

cannot say that HIV-infected women expose their children to a 20 to 30 percent chance of a full-fledged medical disaster on the order of Tay-Sachs. Because at most only 20 percent of infected children fit this description, the odds of any given HIV-infected woman engendering a wrongful life would have to be reduced toward 5 percent. Those are significantly different odds, and it is not at all clear that taking such a risk would violate societal norms of responsible reproductive choice.

High Risk of Serious Harm. A second argument based on the harm principle concedes the low risk of wrongful life, but insists that the overall harm/probability ratio remains decidedly grim for HIV-infected children. They may be better off on average than children with Tay-Sachs, but more than half will die before the age of six, and the remainder must live under a cloud of impending death with progressively deteriorating immune systems. Even though many of these children will have lives that are "minimally decent" or "worth living," the decision to have them might still be faulted under certain circumstances. Instead of allowing only one clear, bright conceptual line, wrongful life, to demarcate the ambit of responsible decision making, the partisans of this second argument would have us view parental responsibility as a complex function of the severity of the child's illness, the probability of a bad outcome, and the availability of other options (Purdy 1989).

Consider an example from Derek Parfit (1976). Suppose a woman is told by her physician that if she gets pregnant while on a certain medication she will give birth to a child with a mild deformity, such as a withered arm; but if she waits a month, she can conceive a perfectly normal child. If the woman refuses to wait and proceeds to have the child with the withered arm, she could be blamed for being irresponsible on the grounds that (a) she has brought a fair amount of gratuitous suffering into the world and (b) she had a readily available alternative.

But what if the woman has no alternative but to risk having an afflicted child, as is currently the case with HIV-infected women? The answer depends primarily on the magnitude and certainty of the evil. If a woman could only have one child who would have to be born with a withered arm, I do not think that it would be terribly irresponsible of her knowingly to conceive such a child. Although it would have been wrong if the woman had an easily available alternative, the absence of other options and the relatively mild nature of the deformity would make her choice permissible, even were the outcome certain.

When we substitute AIDS for the withered arm in this story, the choice seems manifestly irresponsible. It would be wrong *knowingly* to have a child who would surely suffer from a terrible chronic illness and die at the age of four, seven, or ten, even were that child's life, on the whole, worth living. The fact that unconceived or unborn children could end up having lives that were on balance worthwhile cannot function as an all-purpose excuse for imposing grievous pain, suffering, and deprivation on them. Although such children may not, strictly speaking, be "victims" because they presumably have no alternatives to either nonexistence or this particular "minimally decent" life (Parfit 1984), it is still irresponsible and wrong of parents to expose them to a high risk of great suffering.

Because we presently lack this kind of foreknowledge, the crucial question is whether subjecting a child to a 20 to 30 percent chance of HIV infection lies beyond the pale of reproductive responsibility. Given the difficulty of this issue, it is not surprising that our society is sending decidedly mixed messages. On the one hand, the CDC and state departments of health have nearly unanimously recommended that HIV-infected women be advised to avoid future pregnancies. According to one researcher who has polled all state health departments on this question, only New Jersey does not recommend directive counseling to nonpregnant, infected women (Ronald Bayer 1990, personal communication). It could be argued, however, that public-health officials are not an ideal population sample for determining the larger society's views on reproductive responsibility. Their perspective has traditionally focused rather narrowly on preventing the transmission of disease rather than on the comparatively more delicate question of the moral uses of personal privacy rights.

At the other extreme, one could poll genetic counselors to learn that nondirective counseling is the norm across the board, even for diseases like Tay-Sachs. The problem with identifying this group as typical of our society is that it exhibits an opposite bias in favor of personal reproductive autonomy at the expense of all other values, such as harm to others and the just allocation of resources (Wertz and Fletcher 1989).

The very intensity and polarization of the public debate on this matter leads me to conclude that the risk assumed by HIV-infected women is neither clearly responsible nor clearly irresponsible, but rather lies on the margin of societal acceptability. Although the majority in our society no doubt deems such a harm/probability ratio to be extremely

problematic, and although most people would shun this level of risk for their offspring, I do not detect a widespread conviction that others would *always* be wrong to assume such a risk, especially if they have no other options.

Most of this lack of clarity and certainty would be dispelled by a reliable prenatal assay such as the test for maternal antibodies to glycoprotein gp 120. Ability to predict with, say, 85 to 90 percent confidence that any particular HIV-infected woman would give birth to an infected child would almost surely cross the threshold of "unacceptable risk." However, medical advance is a two-edged sword. By the time a highly predictive diagnostic test is available, effective antiviral and prophylactic agents may also be developed, thus considerably lowering the magnitude of the threatened harm.

Burdens to Women

Although my analysis to this point has appropriately focused on child-centered concerns, a full moral accounting requires consideration of the likely burdens that reproductive restraint would impose on HIV-infected women. Because these burdens have already been eloquently catalogued by Carol Levine and Nancy N. Dubler, I shall limit myself to two brief points.

First, as several commentators have pointed out, childbearing has come to assume an overriding importance for women from the affected communities (Gross 1987; Holman et al. 1989). Largely due to the absence of alternative sources of self-realization, satisfaction, and comfort, poor women of color are under intense psychological and social pressures to have children. Asking them to refrain permanently from childbearing may thus amount to asking them to forgo their only remaining source of personal identity and social status.

Secondly, this burden of abnegating motherhood will be made weightier still when abortion is the only remaining means of preventing birth. For women with moral or religious objections, abortion will obviously be an unacceptable means of preventing HIV infection. To insist that these women have a moral duty to abort all fetuses at risk would amount to a violation of their own rights of conscience.

Even for women who approve of abortion in general—indeed, even those who view abortion in these circumstances as their particular moral

duty—abortion remains an option exercised in necessity and sorrow. Contrary to some philosophers' glib comparisons between the moral seriousness of abortion and getting one's hair cut, for most women having an abortion is an occasion of loss and sadness, even when thought to be fully justified. This burden must also be weighed on the scales of moral judgment concerning reproductive responsibility.

Moral Conclusions

Perhaps the most important result of the analysis here is the conclusion that the risk to which children of HIV-infected mothers are exposed, while exceedingly problematic, is not clearly immoral according to our societal standards. If I am right about this, it follows that the presence of HIV infection alone should not be considered a sufficient reason for a judgment of parental irresponsibility. This is not to say that all HIV-infected women act responsibly and morally in deciding to have children—far from it; rather, it is to say that no blanket conclusions can be drawn about the choices of infected women as a class. If this conclusion is correct, then the CDC and state health departments should stop recommending reproductive restraint for *all* infected women.

Although the risks of perinatal HIV infection lie on the margins of societal acceptability, they remain deeply problematic and compel careful moral scrutiny of each and every reproductive choice. Instead of being guided by any blanket rule, such scrutiny should consist in a highly contextualized and sensitive balancing of all of the morally relevant factors discussed above. This approach will yield different conclusions depending upon the particular circumstances of each case.

Let us consider two hypothetical examples drawn from opposite ends of the moral spectrum. First, take the case of Janet, a young woman infected by a previous sex partner. Currently childless, she is now married to an uninfected man who is fully committed to raising a child with her or, if necessary, with the help of a large and devoted extended family. She is currently in good health, having only recently been infected, and could have several good years before the onset of serious HIV disease. Janet finds herself pregnant, deeply desirous of having and loving a child, and very ambivalent about the morality of abortion. Although both she and her husband ought to approach their

choice “in fear and trembling” for the well-being of their child, their decision to go forward with the pregnancy appears justifiable.

Now consider the case of Joan, a homeless crack addict whose three previous children have all been placed in foster care. Having no desire for additional children, she became pregnant trading sex for crack, and has stayed pregnant by default. Although she considers abortion merely to be another form of birth control, and although (in this fictional case) there have been no legal, clinical, or financial barriers to access, Joan has failed to obtain an abortion by default. Drug-seeking behavior has effectively eclipsed all her other concerns. She has been abandoned by her former husband, disowned by her family, and now lives on the streets. She has been infected for a long time, and her health is very poor.

This hypothetical case, a veritable catalogue of all the social ills distilled in the crucible of the AIDS epidemic, elicits conflicting responses. On the one hand, Joan strikes us as a living, breathing indictment of the system that consigned her to the garbage heap of society. We want to ease this woman’s pain, find her decent housing, and provide her with the kind of drug rehabilitation and medical care that she so desperately needs and deserves.

On the other hand, Joan’s “choice”—really a nonchoice—to have this child despite her current lack of desire or ability to provide the child with love, care, and a suitable home, should strike us as a paradigmatic case of parental irresponsibility. Simply put, Joan has no business having additional children, particularly children who would be at risk for HIV infection. We can conclude this even while condemning the society that has turned its back on her and absolving her of any moral blame for her addicted state. The fact remains that she is about to expose another human being to a high risk of a life-threatening illness and social neglect for no good reason. Joan may have the legal right to act as she does, but her behavior in this case is seriously irresponsible and wrong.

These two hypotheticals are of course atypical; the vast majority of cases will fall somewhere between these moral extremes, where there is bound to be a rather large gray area of intractable moral uncertainty. The point in rehearsing them has been to illustrate how particular moral judgments on reproductive responsibility will largely be a function, not exclusively of the harm/probability ratio, but of factors quite adventitiously linked to women’s HIV infection as well. It just so happens that, of all the women infected by this virus, many desperately

want children because of their socioeconomic circumstances, and that many others are desperately addicted to drugs and unable to care for their children. The specific constellation of these morally relevant factors should supplement our indecisive anguish over reproductive risk and guide our moral assessments of particular cases. In many cases, however, even this supplementary moral evidence will not be enough to yield confident conclusions.

Finally, we should recall that the development of a reliable prenatal diagnostic test in the absence of effective treatments for HIV would most likely render otiose this labored, particularistic approach to assessing reproductive choices. Probabilities on the order of 75 to 100 percent of eventual perinatal infection would allow us to view the harm/probability ratio alone as a sufficient indicator of moral irresponsibility.

Implications for Intervention

If the arguments I have presented carry weight, we must try to determine with more precision which kinds of societal intervention into the reproductive decisions of HIV-infected women might be warranted. In this final section, I shall briefly examine the dominant method of nondirective counseling and then consider three alternatives: frankly coercive interventions; a beefed-up "educational model" of nondirective counseling; and noncoercive, "negotiated" directive counseling.

Nondirective Counseling

The counseling of HIV-infected women has by and large followed the nondirective approach developed by genetic counselors rather than the more directive approach usually favored by medical professionals (Wertz and Fletcher 1989). The nondirective model upholds an ideal of "value neutrality" and puts a premium on establishing a trusting, supportive relationship with the client. The counselor's role consists in providing factual information (e.g., the risks of transmission), helping the client understand the meaning of the various alternatives for her own life, and supporting her decision, whatever that happens to be. Although nondirectiveness does not preclude probing the client's initial decision—for example, to discover possible contradictions between her stated preferences and her more deeply held values—the counselor

would not be permitted critically to invoke values other than those the client holds. Recommending any particular course of action is viewed as an unethical usurpation of the client's decision-making authority.

So long as HIV-infected women's reproductive risks remain roughly within the ambit of broadly held views, some version of nondirective counseling would appear to be appropriate. If there is no clear evidence that the decisions of a certain group fall outside of a moral consensus, society lacks the requisite moral authority to articulate a preferred use of reproductive freedom.

Having endorsed nondirective counseling given the current state of medical knowledge, I want to lodge two caveats against this model. One is general and the other specific to its use in HIV-related cases. First, the decision-making authority of clients is not necessarily dependent upon nondirective counseling. Although the first generation of genetic counselors may have had good pragmatic reasons to abandon the more directive approaches associated with discredited eugenic goals (President's Commission 1983), it is simply not true—at least in the abstract—that clients' reproductive rights are necessarily violated by any and all forms of directive counseling. So long as such counseling seeks to alter behavior by means of rational persuasion rather than coercion, it is compatible with the fully voluntary exercise of reproductive rights. Thus, we should not mistake, as do many partisans of nondirective counseling, a pragmatic justification for nondirectiveness in most genetic contexts with some sort of universal, axiomatic, and self-evident moral principle.

Second, nondirective counseling for HIV-infected women appears to be substantially ineffective in altering reproductive decision making. Unlike the largely efficacious role of non-directive counseling for those concerned with Tay-Sachs disease, recent studies suggest that knowledge of one's HIV-positive status, coupled with nondirective counseling, is most likely not a determining factor in decisions to terminate pregnancies. No statistically significant differences in reproductive behavior were found between groups of infected and uninfected drug users in Brooklyn and the Bronx. Over 20 percent in each group became pregnant over a two-year period, and roughly the same percentage (40 percent of seropositives vs. 50 percent of seronegatives) opted for abortion. Of those seropositives who became pregnant, over 25 percent became pregnant a second time (Sunderland et al. 1988; Selwyn et al. 1989).

Although nondirective counseling might be maximally responsive to the autonomy of clients, it appears to do little, if anything, to advance the value of protecting future children from harm. Because supportive nondirectiveness is not theoretically the only approach to counseling compatible with reproductive rights, we appear to have some motivation and ethical warrant to explore other approaches. We need, however, to deal with the charge that any moral arguments on behalf of future children logically entail straightforwardly coercive interventions.

Coercive Interventions

There are two ways to coerce the reproductive behavior of HIV-infected women. First, one can intervene physically, forcing a woman to submit to involuntary sterilization or abortion. From the woman's point of view, such "acts" are entirely divorced from her will. Although a policy of physically coerced "reproductive responsibility" would be maximally responsive to the interests of future children, it would achieve this end through utterly unacceptable violations of the person and rights of women. Although forced sterilization or abortion would be unconscionable even if we had a foolproof prenatal diagnostic screening test for HIV infection, the fact that 70 to 80 percent of the children are born uninfected merely underscores the immorality of this option.

The second modality of coercive intervention would confront the woman with two unwanted alternatives—for example, submitting to an abortion or risking a cutoff of health-care benefits. This kind of coercion works through threats, which constrain, but do not completely annul, the woman's will. She is still able to ponder the alternatives and make a rational choice between them. Such proposals are considered "coercive" because by posing two unacceptable alternatives they threaten to make the woman worse off in terms of her own value preferences than she was prior to the intervention (Feinberg 1986; Wertheimer 1987).

This kind of coercion is morally wrong because, although it does not involve physical violence, it would violate the woman's right to either reproductive liberty or access to medical care. Even though some might think that a woman's particular reproductive choices are unwise or immoral, our social policy is based on a premise of self-determination. Competent women do not and should not have to pass an ethics or "rationality" test in order to exercise their freedom to have or not have

children. They should certainly never be forced to barter their reproductive rights for health care.

A "Moral Education" Model of Nondirective Counseling

This alternative approach to the counselor–client dialogue would be based upon a distinction, articulated by Jay Katz (1984, 110–29), between autonomy as a right of final decision making, which it respects, and unfettered autonomy in the process of deciding, which it rejects. The goal of the educational model is to clarify the client's values and expand her awareness of the moral dimensions of her choices through respectful exchanges, not merely to offer a recitation of the medical facts on HIV transmission.

Counselors would ask whether the client has thought about the suffering she risks imposing on her future child and the likelihood of the child becoming an orphan. Is she denying or underestimating the magnitude or likelihood of infection? Has she considered the impact that an HIV-infected child might have on existing siblings? Are her motives for pregnancy sufficiently weighty, given the deadly serious stakes, or is she failing to consider the potential child's separate dignity and interests? Although counselors would not tell the woman what they think she ought to do, they would attempt to confront her with the full force of the moral dilemmas she actually faces.

Authentic decision-making capacity presupposes an appreciation of the nature and meaning of potential alternatives—what it would be and feel like to be in possible future states and to undergo various experiences (Buchanan and Brock 1986, 25). The educational model would sanction efforts to foster such affective appreciation. For example, counselors could discuss the experiences of other clients who have had HIV-infected children or what it was like for the children and parents as AIDS eventually took its toll.

This model would similarly permit counselors to invite infected women, obtaining their informed consent beforehand, to tour the pediatric AIDS unit at a local hospital to see for themselves what happens to some of the unlucky infants. Advocates for disabled persons approve of this technique, encouraging genetic counselors to facilitate visits of prospective parents to the homes of disabled children (Asch 1989).

AIDS counselors might recommend a visit to the pediatric AIDS unit as a step toward achieving genuinely *informed* decision making. In order to achieve balance, clients could also visit the homes of children who were not HIV infected, although the utility of such an option is not apparent.

Although it deviates significantly from a purely "client centered" approach to nondirective counseling, this model calls attention to the plight of HIV-infected children while refraining from articulating a socially preferred conception of reproductive responsibility. So long as the content of the educational message remains well balanced—and so long as counselors refrain from threatening, badgering, or other forms of verbal intimidation—the approach would offer the prospect of an attractive, noncoercive compromise between respectful but apparently ineffective nondirective counseling and the more highly controversial directive model. Indeed, the kind of personal involvement, observation, and reflection promised by this model could well prove even more effective in altering infected women's behavior than frankly directive counseling based only upon the recitation of abstract statistics.

Negotiated Directive Counseling

A more controversial, but possibly justifiable, counseling model would abandon the widespread professional ideology of supportive nondirectiveness in those cases where decisions deviate significantly from a social consensus on reproductive responsibility. Clients like Joan, the homeless crack addict and demonstrably unfit mother discussed above, would presently qualify as a candidate for directive counseling. Likewise, the future development of a reliable prenatal diagnostic test might justify directive counseling for women whose fetuses proved to be at risk.

In addition to engaging in the kinds of discussion appropriate to nondirective and "educational" counselors, directive counselors would make a forthright recommendation to avoid pregnancy or to have an abortion. They would emphatically acknowledge women's moral and legal rights to make reproductive decisions according to their own standards of risk assessment, and sympathize with their desire for more children. However, they would disagree with particular women's unwillingness to assume parental responsibilities for their child or with

their willingness to expose their future children to, say, an 85 percent chance of infection with the AIDS virus.

This kind of directive counseling, like any other kind of clinically responsible service, would have to be carefully contextualized, especially with regard to abortion counseling. Some women believe that abortion, even for the "fetus's own sake," is immoral. Before making a recommendation to abort, counselors would have to be knowledgeable about women's views on this matter.

The voluntary, noncoercive nature of this model would have to be underscored. Counselors would have to preface and conclude their advice with a firm and genuine reminder that the choice is ultimately the woman's to make, that their *recommendation* is precisely that and nothing more. This approach thus differs greatly from coercive variants of directive counseling that attempt to skew the woman's reasoning process and judgment by means of threats, enticements, and verbal intimidation.

As a moral precondition of this approach, counselors would have to *negotiate* through open dialogue with the client about the mutual acceptability of a directive approach that significantly deviates from current professional norms. Any overtly directive counseling, that is, would be preceded by obtaining the client's free and informed consent. Thus, in addition to offering information and seeking to clarify values, counselors would make a recommendation if a woman wishes to hear it. (I derive this notion of "negotiated" directive counseling from a communication with John Fletcher.)

This last requirement might strike some people as odd or unnecessary. If such counseling is supposed to be genuinely noncoercive, consisting of advice rather than overt or veiled threats, why should one have to secure the client's prior informed consent?

In the abstract, there is a point to this objection. If directive counseling, so defined, is entirely noncoercive, counselors have no apparent ethical duty to obtain consent merely to offer nonbinding advice. The requirement is based, however, on the concrete social reality that "officially sanctioned" directive counseling is not currently channeled to any other social groups, including the carriers of Tay-Sachs disease. Put another way, obtaining prior consent to directive counseling is based on concern for the "moral equal protection" of the members of this most vulnerable social group.

Conclusions and Some Reservations about Directiveness

I conclude that of the four counseling models surveyed, the moral education model is the most appropriate at this time for the majority of HIV-infected women. While it is nondirective about the eventual *content* of the woman's choice, this model insists that the *process* of reaching a decision include a forthright discussion of the ethical dilemmas posed by reproduction under the specter of AIDS. Although acknowledging women's right to choose according to their own lights, and refraining from articulating a preferred societal conclusion, the moral education model would reject the notion that women have a moral right to waive a serious ethical consideration of possible grave harm to others. Practitioners of this model could also, of course, be emotionally supportive of the woman's eventual decision, whatever that might be, but only *after* she has pondered, to the best of her abilities, the moral dilemma in all its force and complexity.

Should a reliable (e.g., 80 to 100 percent) prenatal test for eventual pediatric seropositivity be developed in the absence of vastly improved therapeutics for AIDS, some form of blanket directive counseling, preferably negotiated, might be justified. Although I find this model of directive counseling to be fully consonant with women's moral agency, two caveats are in order.

One very serious problem concerns the likely long-term consequences of implementing an ideal model of directive counseling in the real world. Whereas ideal directive counselors would neither coerce nor intimidate their clients in any way, scrupulously honoring their reproductive rights, in the real world of understaffed, overcrowded, depersonalized inner-city health clinics, things might not work out as planned. Harried and frustrated at best, insensitive and racist at worst, counselors in what has been aptly called the "medical third world" of inner-city AIDS might well be tempted to coerce their vulnerable clients in accord with their own societal agendas. To borrow a phrase from a leading critical theorist, real-world encounters between AIDS counselors and HIV-infected women might well be tainted by "systematically distorted communication" (Habermas 1980). The participants in this dialogue are already separated by tremendous disparities of power, race, and class. In view of the dependency of these women on the medical establishment for

whatever small amount of care, often in the form of methadone, that they receive, it may be dangerously naive to assume that the widespread practice of directive counseling will not have subtly coercive long-term effects.

Although abuse is possible with any approach to counseling, it is not obvious to me that such widespread coercion would in fact occur. In the first place, the requirement of prior informed consent would give the client an effective veto power over the use of directive counseling. My own discussions with AIDS counselors and caregivers from the Bronx, Brooklyn, and Manhattan provide additional reassurance. In meeting after meeting on this issue, the counselors I have encountered have been vociferously and almost universally hostile to nonnegotiated directive counseling because of its perceived threat to women's reproductive rights. In any case, a program of directive counseling would have to be very carefully implemented and periodically monitored, ideally with the help of the client population.

A second problem concerns the prospects of any kind of counseling to change behavior in socially desirable ways. The record of nondirective counseling has so far been consistently disappointing. Even the mild form of directive counseling advocated by the CDC—that infected women postpone pregnancies until more is known about HIV (Centers for Disease Control 1985)—appears to have had little, if any, effect. Whether the “moral educational” or “negotiated directive” models would be more effective is difficult to predict. Practitioners of directive counseling will have an especially difficult task attempting to encourage reproductive restraint without becoming reproachful and alienating their clients. Respectful dialogue will remain the cornerstone of successful counseling.

Perhaps the most formidable barrier to behavior change, however, lodges in the ethnic and political dimensions of this debate. So long as the issue is seen as a case of white, middle-class professionals telling poor women of color not to have babies, heated charges of racism and genocide are likely to claim center stage, forcing a legitimate concern for the suffering of children to the wings. So long as HIV-infected clients regard their counselors as foreign “others,” as emissaries of an alien sociomedical establishment, they will remain resistant, if not actively hostile, to the suggestion that they forgo further childbearing.

As the history of genetic counseling for Tay-Sachs carriers attests

(President's Commission 1983), the support of the local community is required to change reproductive behavior. Effective preventive interventions will require the voluntary and communal alteration of deeply held values and cultural traditions. If counselors' messages are not endorsed by supportive echoes in families, churches, schools, clinics, and community newspapers, they will most likely fall on deaf ears.

One important way to address the problem of ethnic conflict might be to introduce both the educational and negotiated directive models in the less threatening environment of peer counseling rather than traditional "expert-client" encounters. Persons from the affected communities who appreciate the seriousness of the risks, empathize with their fellow citizens, and speak with credibility among their peers should be selected for this kind of counseling.

It may well turn out, however, that in spite of the best efforts of such counselors, the model of directive counseling would prove unacceptable both clinically and politically within the affected communities. In the event of such intractable disagreement about the boundaries of acceptable risk between representatives of the societal mainstream and particular subcultures, other ways of decreasing the spread of perinatal HIV infection will have to be explored. The burden of this article has in part been merely to show that negotiated directive counseling can be morally justified under certain conditions. Whether its widespread deployment will be clinically effective or politically wise are separate questions deserving of serious further inquiry.

References

- Andiman, W., B.J. Simpson, B. Olsen et al. 1990. Rate of Transmission of Human Immunodeficiency Virus Type 1 Infection from Mother to Child and Short-term Outcome of Neonatal Infection. *American Journal of Diseases of Children* 144 (July):758-66.
- Asch, A. 1989. Reproductive Technology and Disability. In *Reproductive Laws for the 1990s*, ed. S. Cohen and N. Taub. Clifton, N.J.: Humana.
- Bayer, R. 1989. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New York: Free Press.
- Buchanan, A. and D.W. Brock. 1986. Deciding for Others. *Milbank Quarterly* 64 (Suppl. 2):17-94.
- Callahan, S. 1979. An Ethical Analysis of Responsible Parenthood. In

- Genetic Counselling: Facts, Values, and Norms*, ed. A.M. Capron, M. Lappé, R.F. Murray et al., 217–38. New York: Alan R. Liss.
- Callahan, D. 1981. Minimalist Ethics. *Hastings Center Report* 11(5): 19–25.
- Centers for Disease Control. 1985. Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-associated Virus and Acquired Immunodeficiency Syndrome. *Morbidity and Mortality Weekly Report* 34:721–32.
- . 1990. *HIV/AIDS Surveillance Report*. (April) Atlanta.
- Devash, Y., T. Calvell, D. Wood et al. 1990. Vertical Transmission of Human Immunodeficiency Virus Is Correlated with the Absence of High-affinity/Avidity Maternal Antibodies to the gp120 Principal Neutralizing Domain. *Proceedings of the National Academy of Sciences*. 83:3445–49.
- Falloon, J., J. Eddy, L. Wiener, and P.A. Pizzo. 1989. Human Immunodeficiency Virus Infection in Children. *Journal of Pediatrics* 114(1):1–30.
- Feinberg, J. 1984. *Harm to Others*. New York: Oxford University Press.
- . 1986. *Harm to Self*. New York: Oxford University Press.
- . 1988. Wrongful Life and the Counterfactual Element in Harming. *Social Philosophy and Policy* 4(1):145–78.
- Goedert, J.J., H. Mendez, J.E. Drummond et al. 1989. Mother-to-infant Transmission of Human Immunodeficiency Virus Type 1: Association with Prematurity or Low Anti-gp120. *The Lancet* 8678 (Dec. 9):1351–54.
- Gross, J. 1989. The Most Tragic Victims of AIDS: Thousands of Children. *New York Times*: July 17, B4.
- . 1987. The Bleak and Lonely Lives of Women Who Carry AIDS. *New York Times*: August 27, A1.
- Gwinn, M. 1990. Data presented at Institute of Medicine Conference, Prenatal and Newborn Screening for HIV Infection: Opportunities for Prevention and Treatment, Washington, May 14.
- Habermas, J. 1980. The Hermeneutic Claim to Universality. In *Contemporary Hermeneutics*, ed. J. Bleicher, 181–211. London: Routledge & Kegan Paul.
- Holman, S., M. Berthaud, A. Sunderland et al., 1989. Women Infected with Human Immunodeficiency Virus: Counseling and Testing during Pregnancy. *Seminars in Perinatology* 13(1):7–15.
- Katz, J. 1984. *The Silent World of Doctor and Patient*. New York: Free Press.
- Mill, J.S. 1859. *On Liberty*. (Revised ed. 1957, ed. D. Spitz. New York: W.W. Norton.)

- Novick, L.F., D. Berns, R. Stricof et al. 1989. HIV Seroprevalence in Newborns in New York State. *Journal of the American Medical Association* 261(12):1745-50.
- Parfit, D. 1976. On Doing the Best for Our Children. In *Ethics and Population*, ed. M.D. Bayles, Cambridge, Mass.: Schenkman.
- . 1984. *Reasons and Persons*. Oxford: Oxford University Press.
- Pizzo, P. 1989. Emerging Concepts in the Treatment of HIV Infection in Children. *Journal of the American Medical Association* 262(14): 1989-92.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1983. *Screening and Counselling for Genetic Conditions*. Washington.
- Purdy, L.M. 1989. Genetic Diseases: Can Having Children Be Immoral? In *Ethical Issues in Modern Medicine*, 3rd ed., ed. J. Arras and N. Rhoden, 311-17. Mountain View, Calif.: Mayfield.
- Rescher, N. 1983. *Risk: A Philosophical Introduction to the Theory of Risk Evaluation and Management*. New York: University Press of America.
- Rossi, P., V. Mosehese, P.A. Broliden et al. 1989. Presence of Maternal Antibodies to Human Immunodeficiency Virus 1 Envelope Glycoprotein gp120 Epitopes Correlates with the Uninfected Status of Children Born to Seropositive Mothers. *Proceedings of the National Academy of Sciences* 86(October): 8055-58.
- Ryder, R.W., and S.E. Hassig. 1988. The Epidemiology of Perinatal Transmission of HIV. *AIDS* 2(Suppl. 1):S83-S89.
- Scott, G.B., C. Hutto, R.W. Makuch et al. 1989. Survival in Children with Perinatally Acquired Human Immunodeficiency Virus Type 1 Infection. *New England Journal of Medicine* 321(26):1791-96.
- Selwyn, P.A., E.E. Schoenbaum, K. Davenny et al. 1989. Prospective Study of Human Immunodeficiency Virus Infection and Pregnancy Outcomes in Intravenous Drug Users. *Journal of the American Medical Association* 261(9):1289-94.
- Septimus, A. 1989. Psycho-Social Aspects of Caring for Families of Infants Infected with Human Immunodeficiency Virus. *Seminars in Perinatology* 13(1):49-54.
- Steinbock, B. In press. *Life before Birth: The Moral and Legal Status of Embryos and Fetuses*. New York: Oxford University Press.
- Stratton, P., L. Mofenson, A. Willoughby. 1990. HIV Infection in Pregnant Women under Care at Clinical Trials Centers in the United States. Presented at 6th International Conference on AIDS, San Francisco, June. (Abstract.)
- Sunderland, A., G. Moroso, M. Berthaud, et al. 1988. Influence of HIV Infection on Pregnancy Decisions. Fourth International Conference on AIDS, Stockholm, Sweden. (Abstract 6607.)

- Wertheimer, A. 1987. *Coercion*. Princeton: Princeton University Press.
- Wertz, D. and J. Fletcher. 1989. *Ethics and Human Genetics: A Cross-cultural Perspective*. Heidelberg: Springer-Verlag.

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Address correspondence to: John D. Arras, Ph.D., Department of Epidemiology and Social Medicine, Montefiore Medical Center, 111 East 210th Street, Bronx, NY 10467.