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HIV AND ART: REPRODUCTIVE CHOICES AND CHALLENGES

*Nanette R. Elster, J.D., M.P.H.**

INTRODUCTION

Long before the human immunodeficiency virus (HIV) epidemic and the birth of the first “test-tube” baby, the Supreme Court held that “[I]f the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision to bear or beget a child.”¹ This right continues to be regarded as one of the most fundamental rights we have in the United States. In fact, in 1992, the Supreme Court reaffirmed the “recognized protection accorded to the liberty relating to intimate relationships, the family, and decisions about whether to bear and beget a child.”² And, according to law professor John Robertson, “procreative liberty should enjoy presumptive primacy when conflicts about its exercise arise because . . . [it] is central to personal identity, to dignity and to the meaning of one’s life.”³

Against this backdrop in which childbearing decisions are afforded the utmost protection, should the reproductive choices of those infected with HIV be any less protected? Should the right to reproduce with the assistance of technology such as in vitro fertilization (IVF) be any less protected? For the past two decades these are issues that continue to be debated. In fact, until recently, denying HIV-positive individuals access to assisted reproduction was not only commonplace, but the recommended course of action by medical experts.

Concern about liability is one of the key reasons that some fertility programs denied, and continue to deny, infertility services to HIV-

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1. Eisenstadt v. Baird, 405 U.S. 438, 453 (1972).
2. Planned Parenthood v. Casey, 505 U.S. 833, 857 (1992).
3. John A. Robertson, Children Of Choice: Freedom and the New Reproductive Technologies , 24 (1994).

positive patients.⁴ One medical program issued a memorandum to all of their IVF patients dated April 2, 1999, which stated,

Given that vertical transmission rate for HIV are not zero and may be at minimum 2-7% and possibly much higher, IVF services will not be offered to HIV-positive women. From a medical perspective, we would like to obviate the possibility that an individual infected with HIV is delivered as a result of our intervention. From a legal perspective, we wish to avoid liability for wrongful birth prosecution.⁵

Liability, however, may also arise from the decision to deny such services.

HISTORY OF INFERTILITY SERVICES FOR HIV-POSITIVE INDIVIDUALS

Historically, couples affected by HIV have been denied access to infertility services as a result of a range of health and safety concerns. For example, in the early 1990's both the American Fertility Society, now the American Society for Reproductive Medicine (ASRM) and the Centers for Disease Control (CDC) issued guidelines recommending against providing infertility treatment to couples with HIV.⁶ The guidelines were a reaction to a report that HIV had been transmitted to a woman who had been inseminated from her hemophiliac husband, who was HIV-positive.⁷ Additionally, concerns about vertical transmission of HIV to infants at a rate of about 25% as well as concerns about endangering lab personnel and contaminating other samples reinforced the wisdom of these guidelines. At this same time, some states were enacting legislation, imposing criminal liability for performing artificial insemination using semen of a donor who has tested positive for HIV,⁸ and on one who "transfers, donates, or provides his or her blood, tissue, semen, organs, or other potentially infectious body fluids for . . . insemination . . ."⁹

4. See, e.g., Deborah J. Anderson, *Assisted Reproduction for Couples Infected with the Human Immunodeficiency Virus Type 1*, 72 FERTILITY AND STERILITY 592, 593 (1999); Erika Blacksher, John Yeast, & David J. Warse, *A Request for ICSI*, 30 HASTINGS CENTER REPORT 23 (2000).

5. Memorandum from Director, Division of Reproductive Endocrinology and Infertility, WRAMC, at <http://www.wramc.ameddd.army.mil/departments/gyn/repro/policies/hiv.htm> (last visited Feb. 6, 2003).

6. See, e.g., Anderson, *supra* note 4.

7. *Id.* (citations omitted).

8. See, e.g., 20 ILL. COMP. STAT. 231/2310-325 (2000).

9. 720 ILL. COMP. STAT. 5/12-16.2 (2000).

Social concerns were also raised as a reason to deny fertility treatment to HIV-positive couples. Who would care for the child should one or both parents become ill or die? What would happen if the child were to become ill as well? Would society then bear the financial responsibility for caring for this family?

MEDICAL ADVANCES IN TREATING HIV AND IN TREATING INFERTILITY

Since the mid-1990's dramatic advances in the treatment of HIV have made it possible for those infected to live longer, less symptomatic lives. According to one commentator, HIV "is now classified as a chronic disease by infectious disease experts, and it is expected that many HIV-infected individuals will live healthy lives. Further, antiretroviral drugs have reduced the rate of vertical transmission of HIV-1 from mother to infant to [less than] 10%."¹⁰ Contemporaneously, advances in reproductive technologies have increased the range of techniques available to achieve a pregnancy.

The combination of these scientific and medical developments may make having children a more realistic and safer option for HIV-positive couples. In fact, a survey done by the Alan Guttmacher Institute of HIV-positive men and women found that "28% of HIV-positive men and 29% of HIV-positive women desire children in the future."¹¹ While there are still risks, many couples are willing to take the chance. One woman, for example, whose husband, a hemophiliac, contracted HIV from contaminated blood, decided to undergo artificial insemination utilizing her husband's "washed sperm."¹² She said, "I knew the risks. But at the same time, I knew I could get hit by a car backing out of my driveway. My risk of that was higher than my risk of getting HIV."¹³ The couple gave birth to a healthy daughter,

10. Anderson, *supra* note 4, at 592 (citations omitted).

11. James L. Chen, Kathryn A. Phillips, et al., *Fertility Desires and Intentions of HIV-Positive Men and Women*, 33 FAMILY PLANNING PERSPECTIVES 144, 150 (July 2001).

12. Lisa Frazier, *Seeking a Safe Path Toward Fatherhood*, WASH. POST, Apr. 19, 1999, at A1. The production of "washed sperm," is accomplished by preparing semen samples "with use of Percoll gradient washing and swim-up technique." Anne Drapkin Lysterly & Jean Anderson, *Human Immunodeficiency and Assisted Reproduction: Reconsidering Evidence, Reframing Ethics*, 75 FERTILITY AND STERILITY 843-858 (2001).

13. Frazier, *supra* note 12.

and both mother and daughter tested negative for HIV six months after the child's birth.¹⁴

A physician in Italy surveyed more than 1000 insemination attempts utilizing "washed sperm."¹⁵ Of the 350 couples, where the male partner was HIV-positive and the female partner was not infected, there were nearly 200 subsequent births and no seroconversion occurred in the female partner, and none of the children became infected.¹⁶ In addition, an article published in the January 2001 issue of *Fertility and Sterility* reported that two uninfected children were born as a result of pregnancies utilizing intracytoplasmic sperm injection (ICSI) in a serodiscordant couple.¹⁷ The authors asserted that "[a]s ICSI involves fertilization of the oocyte with a single spermatozoon, it can be assumed that the risk of infecting the woman is lower than in other assisted reproduction techniques."¹⁸ More recently, in April 2002, Sauer and Chang published results finding no seroconversion in thirty-four women and their twenty-five offspring following fifty-five embryo transfers using ICSI and sperm washing.¹⁹ Based on the advances in utilizing fertility treatments to reduce the horizontal and vertical transmission of HIV, one practitioner recommended that ASRM "revisit its recommendations concerning ART services for HIV-1-infected couples."²⁰

This is precisely what the Ethics Committee of ASRM has done. In 2002, the Committee published a new statement in the journal *Fertility and Sterility* acknowledging the need to update their recommendations

14. *Id.*

15. A.E. Semprini, et al., *Assisted Conception to Reduce the Risk of Male-to-Female Sexual Transfer of HIV in Serodiscordant Couples: An Update* [abstract], cited in Ethics Committee of the American Society for Reproductive Medicine, *Human Immunodeficiency Virus and Infertility Treatment*, 77 FERTILITY AND STERILITY 218, 218-222 (2002).

16. See Augusto Semprini, Simona Fiore, & Giorgio Pardi, *Reproductive Counseling for HIV-discordant Couples*, 349 THE LANCET 1401 (May 10, 1997).

17. Dimitris Loutradis, et al., *Birth of Two Infants Who Were Seronegative for Human Immunodeficiency Virus Type 1 (HIV-1) After Intracytoplasmic Injection of Sperm from HIV-1-Seropositive Men*, 75(1) FERTILITY AND STERILITY 210 (2001).

18. *Id.*

19. Mark Sauer & Peter Chang, *Establishing a Clinical Program for Human Immunodeficiency Virus 1-Seropositive Men to Father Seronegative Children by Means of In Vitro Fertilization with Intracytoplasmic Sperm Injection*, 186 AM. J. OBSTET. GYNECOL. 627 (April 2002).

20. Anderson, *supra* note 4, at 593.

to reflect the advances in medicine.²¹ Rather than recommending an across the board denial of treatment for affected couples, the Committee concluded that “[w]hen an affected couple requests assistance to have their own genetically related child, they are best advised to seek care at institutions with the facilities that can provide the most effective evaluation, treatment, and follow-up.”²²

LEGAL AND ETHICAL CONSIDERATIONS

Existing laws and professional society guidelines have not been updated to reflect scientific advances. With these new developments, do the same health and safety imperatives exist to continue to limit access to fertility services for those infected with HIV? Do the same social concerns exist? Might the denial of services to HIV-infected individuals be considered to be a form of discrimination? There are no clear-cut answers to these questions, but an overview of the potential areas of liability will provide a better understanding of the needs and concerns of HIV-positive couples seeking access to infertility services, as well as the needs and concerns of those providing such services.

Using assisted reproductive technologies (ARTs) to assist or enable HIV-positive couples or other couples with infectious diseases such as hepatitis to achieve a pregnancy, raise a range of legal and ethical questions. A number of risks must be evaluated including: the impact of pregnancy on the health and well-being of an infected woman, the risk of transmission to an uninfected partner, the risk of vertical transmission, the risk of transmission to laboratory personnel who will be handling specimens from infected patients and the risk of contamination of other patients' samples. While such risks exist, the facts and circumstances of each situation must be considered carefully as each risk could lead to liability with respect to patients, lab personnel and any child that may be born.

The ADA

The enactment of the Americans with Disabilities Act (ADA), and its subsequent interpretation with respect to HIV in the pivotal case of

21. Ethics Committee of the American Society for Reproductive Medicine, *Human Immunodeficiency Virus and Infertility Treatment*, 77 FERTILITY AND STERILITY 218 (2002).

22. *Id.*

Bragdon v. Abbott,²³ have left many health care professionals wondering whether they may be liable for denying fertility treatment to HIV-positive couples. Under the ADA, “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases, . . . or operates a place of public accommodation.”²⁴ In addition, the term “public accommodation” is defined by the Act to include “the professional office of a health care provider.”²⁵

In *Bragdon*, patient Sidney Abbott went to the dental office of Randon Bragdon, where she responded to a questionnaire on which she openly disclosed her HIV status.²⁶ After the exam, Dr. Bragdon determined that Ms. Abbott needed a cavity filled and informed Ms. Abbott that it was his policy not to treat HIV-infected patients in his office. (Cite to facts of the case here) However, he told Ms. Abbott that he would fill the cavity in the hospital if she were willing to pay the hospital costs.²⁷ Ms. Abbott was unwilling to agree to this and subsequently filed a claim against Dr. Bragdon under the ADA, asserting that she had been discriminated against based on her disability.²⁸ The claim went all the way up to the United States Supreme Court.

To make a claim under the ADA, one must prove that she suffers from a disability and that the disability substantially limits a major life activity.²⁹ The Court found that Sidney Abbott did, in fact, satisfy this burden. In this case, the major life activity Ms. Bragdon claimed was limited, was her ability to reproduce.³⁰ The Court agreed, holding that “[r]eproduction and the sexual dynamics surrounding it are central to the life process itself.”³¹ However, the Court did recognize that “conception and childbirth are not impossible for an HIV victim but, without doubt, are dangerous to the public health. This meets the definition of a substantial limitation.”³²

23. *Bragdon v. Abbott*, 524 U.S. 624 (1998).

24. 42 U.S.C. § 12182 (2001).

25. 42 U.S.C. § 12102 *et seq.* (2001).

26. *Bragdon*, 524 U.S. at 629-630.

27. *Id.* at 630.

28. *Id.*

29. 42 U.S.C. § 12101 *et seq.* (2001).

30. *Bragdon*, 524 U.S. at 631.

31. *Id.* at 638.

32. *Id.* at 641.

The ADA is not without limitations, though. The Act specifically states that, “Nothing in this title shall require an entity to permit an individual to participate in or benefit from the goods, services, facilities, privileges, advantages and accommodations of such entity where such individual poses a direct threat to the health or safety of others.”³³ However, the burden of proving this “direct threat” rests with the one denying services.³⁴ According to the Court, “the risk assessment must be based on medical or other objective evidence.”³⁵ Such evidence might include “the views of public health authorities, such as the US Public Health Service, CDC, and the National Institutes of Health . . . The views of these organizations are not conclusive, however.”³⁶ On remand, the First Circuit Court of Appeals determined that Dr. Bragdon failed to satisfy this burden of proving a “direct threat.”³⁷

This Court decision could significantly impact the handling of samples from HIV-positive patients. The decision suggests that a blanket denial of services to one infected with HIV may be tantamount to discrimination unless providing such treatment poses a risk of harm to others that cannot be eliminated through some form of accommodation.

As a federal law, the ADA would preempt existing state laws unless such laws provided stronger protections. Additionally, professional society guidelines are purely voluntary and do not have the force of laws or regulations. These laws and guidelines were promulgated in the late 1980s and early 1990s in advance of medical techniques such as prenatal and perinatal treatment regimes that might greatly reduce the risk of transmission of HIV to female partners, male partners and the child. In an article published in the *New England Journal of Medicine*, the authors assert “the change in the face of the epidemic since before the era of highly active antiretroviral therapy, when many policies regarding the use of assisted-reproduction techniques for infected women were set, has been remarkable.”³⁸

With HIV and other infectious diseases, if one can prove that the denial of services is based on a concern that the patient’s infection

33. 42 U.S.C. §12182 (b)(3) (2001).

34. See *Bragdon*, 524 U.S. at 649.

35. *Bragdon*, 524 U.S. at 649.

36. *Id.* at 650.

37. *Abbott v. Bragdon*, 163 F.3d 87 (1st Cir. 1998).

38. Howard Minkoff & Nanette Santoro, *Ethical Considerations in the Treatment of Infertility in Women with Human Immunodeficiency Virus Infection*, 342 NEW ENG. J. MED. 1748, 1748 (2000).

“poses a direct threat to the health and safety of others,”³⁹ then such denial may be found permissible and not discriminatory if it is supported by evidence. Under the Act, a direct threat is one that poses “a significant risk to the health and safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.”⁴⁰ Arguably, handling samples from HIV-positive or hepatitis infected patients does pose a risk to the health and safety of others: there is the risk of vertical transmission to the child, the risk of infecting a female partner if she is inseminated with sperm from her HIV-positive partner; the risk of cross-contamination of other samples stored in the laboratory; and the risk of transmission to the lab personnel responsible for handling the samples.

Each of these risks, as evidenced in current medical literature, may be eliminated or greatly reduced by modifications. For example, in the United Kingdom, to avoid cross-contamination of specimens infected with hepatitis C, there is a separate storage facility.⁴¹ Here in the United States, Harvard researcher Anne Kiessling and her colleagues who have started a program to assist HIV-positive couples conceive, have set up an embryology lab in a camper outside of the clinic to insure that HIV-positive specimens will not intermingle with specimens from other patients.⁴² The Food and Drug Administration (FDA) has issued a proposed rule on Cellular and Tissue-Based Products that would require that if a partner is determined to be an unsuitable donor (i.e. infected with HIV, hepatitis or certain other infectious diseases), the reproductive tissue would be kept physically separate from other products until it was transferred to the designated recipient.⁴³ The proposed rule would also require that the sample be labeled a biohazard.⁴⁴ These requirements are designed to protect those who might be handling the samples. Similarly, the European Society of Human Reproduction and Embryology (ESHRE) Guidelines for Good Practice in IVF Laboratories recommend, “[w]hen a patient is known to be a source of infection risk, a system of

39. 42 U.S.C. § 12182.

40. *Id.*

41. T.B. Hargreave & Chhanda Ghosh, *The Impact of HIV on a Fertility Problems Clinic*, 41 J. REPRODUCTIVE IMMUNOLOGY 261, 266 (1998),.

42. *Couples Having Babies When One or Both Partners is Infected with the AIDS Virus* (NPR radio broadcast Sept. 7, 1999).

43. Suitability Determination for Donors, 64 Fed. Reg. 52696, 52719 (proposed September 30, 1999) (to be codified at 40 C.F.R. pt. 1271).

44. *Id.*

separate storage should be considered.”⁴⁵ In addition, some ART programs that handle samples from hepatitis B and C infected individuals provide separate storage for their embryos.⁴⁶

Other Potential Causes of Action

The problem of vertical transmission remains a thorny one. While treatment regimes have evolved which greatly reduce the risk of perinatal transmission of HIV, the question remains whether any risk to a child is too great? Most recently, it has been found that C-section combined with AZT therapy can reduce the rate of vertical transmission to approximately 2%.⁴⁷ To put this figure in context, a healthy couple has about a 3% chance of having a child with a birth defect.⁴⁸ A couple in which both partners are carriers of a recessive genetic disorder such as Tay Sachs or Cystic Fibrosis has a 25% chance of conceiving an affected child. It is unlikely that the couple would be denied fertility services based upon their risk of conceiving an affected child in either situation. (Albeit, in neither situation is there a risk to the health of other patients, or lab personnel. Given that “parental reproductive decision-making for genetic and other diagnosable prenatal diseases and disorders is typically a matter of private choice, not socially legislated or judicial choice,”⁴⁹ should health care providers be making the decision as to whether this risk is too great or who can choose to assume such risk? Before addressing this point, it is important to recognize that the ADA is not the only source of potential liability; traditional tort causes of actions exist as well. As previously discussed, fears about liability for spreading an infectious disease (i.e. public health concerns), have been the impetus for refusals to treat couples in which one or both partners is infected with HIV, or hepatitis, and for the implementation of policies to that effect.

45. Luca Gianroli, et al., *ESHRE Guidelines for good Practice in IVF Laboratories*, 15(10) HUMAN REPRODUCTION 2241, 2245 (2000).

46. See Anne Drapkin Lyerly & Jean Anderson, *Human Immunodeficiency Virus and Assisted Reproduction: Reconsidering Evidence, Reframing Ethics*, 75 FERTILITY AND STERILITY 843, 848 (May 2001).

47. See Minkoff, *supra* note 38, at 1748.

48. See, e.g., Center for Disease Control at www.cdc.gov/programs/defects.htm.

49. Karen Rothenberg, *Reproductive Choice and Reality: An Assessment of Tort Liability for Health-Care Providers and Women with HIV/AIDS*, in *HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES* 199 (R.Faden & N. Kass eds., Oxford University Press 1996).

If an uninfected couple were to become infected as a result of cross-contamination, they may have a cause of action against the health care providers, if they can prove that the contamination was a result of negligence. To prove a cause of action for negligence, a plaintiff must prove that the defendant owed him a duty, the duty was breached, breach of that duty was the proximate cause of the harm suffered, and damages resulted.⁵⁰ So, in this example, lab personnel would have a duty to follow safe lab practices, and if they failed to do so, by, for example, failing to sterilize the needed equipment or maintain separate storage for infected specimens, and the plaintiff can prove that this caused his harm, and subsequent damages, then liability would likely result.

A more difficult case may arise when, despite all precautions and application of the most updated treatment regime, the child is born infected with HIV. In this instance, not only might the parents have a cause of action, but the child might as well. The parents might have a claim for wrongful birth, and the child might have a claim for wrongful life.

A claim for “wrongful birth” is brought by the parents of a child against a health care professional who “‘failed to inform parents of the increased possibility that the mother would give birth to a child suffering from a birth defect . . . [thereby precluding] an informed decision about whether to have the child.’”⁵¹ A “wrongful life” action is one in which the child “sues for damages, claiming that he would have been better off never having lived at all and, but for defendant’s negligence, would not in fact have lived.”⁵² Under either cause of action, the plaintiff must make the same prima facie case for negligence: duty, breach of duty, causation, and damages.⁵³

These causes of action are typically raised when a child is born with a genetic, or congenital, anomaly that was not diagnosed prior to the child’s birth. This could be caused by the failure to diagnose the anomaly, the failure to provide appropriate testing, or inadequately informing parents of such risk. In *Becker v. Schwartz*, the Court of Appeals of New York held that parents could recover costs for raising a disabled child under a wrongful birth action where the physician had

50. See, RESTATEMENT (SECOND) OF TORTS § 328 (1965).

51. LORI ANDREWS, *MEDICAL GENETICS: A LEGAL FRONTIER* 138 (American Bar Foundation 1987) (citation omitted).

52. Mark Strasser, *Wrongful Life, Wrongful Birth, Wrongful Death, and the Right to Refuse Treatment: Can Reasonable Jurisdictions recognize all but One?*, 64 MO. LAW REV. 29, 29 (1999).

53. See RESTATEMENT, *supra* note 50.

a duty to provide the parents with sufficient prenatal information, enabling them to make an informed choice about whether to abort an affected child.⁵⁴ This same court, however, refused to recognize a cause of action for wrongful life, asserting that

[w]hether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and theologians Simply put, a cause of action brought on behalf of an infant seeking recovery for wrongful life demands a calculation of damages dependent upon a comparison between the Hobson's choice of life in an impaired state and nonexistence.⁵⁵

This decision reflects the current status of these two causes of action across the nation: twenty-two states have judicially recognized wrongful birth claims, while nine states specifically ban such a cause of action.⁵⁶ By comparison, only three states specifically recognize a cause of action for wrongful life, and nine states explicitly ban this claim.⁵⁷ More recently, some legal scholars have suggested a cause of action for wrongful life as a legal remedy for an HIV-infected newborn.⁵⁸ One commentator asserted that “[i]mposing liability on the physician or laboratory for the child born HIV-positive would force health care providers to adopt more reasonable standards for testing and counseling pregnant women.”⁵⁹

An extensive, and detailed, informed consent process may be one way to avert not only claims of wrongful birth or wrongful life, but also many other potential tort causes of action. Communication with patients is an essential, and important factor in reducing liability. In fact, one study indicated that when a poor outcome occurs, and communication was inadequate, a lawsuit is more likely.⁶⁰ Informed

54. See, *Becker v. Schwartz*, 386 N.E.2d 807, 814 (N.Y. 1978).

55. *Id.* at 812.

56. Michelle Hibbert, *Wrongful Birth: Shaping the Next Generation Through Negligence Actions*, in CHANGING CONCEPTIONS: A SYMPOSIUM ON REPRODUCTIVE TECHNOLOGIES (December 5, 1997).

57. *Id.*

58. See, e.g., John F. Hernandez, *Perinatal Transmission of HIV: Cause for the Resurrection of Wrongful Life*, 27 J. MARSHALL L. REV. 393 (1994); Tara C. Fappiano, *Finding a Legal Remedy for the HIV-Positive Infant: Wrongful Live and Lack of Informed Consent Explored*, 12 ST. JOHN'S J.L. COMM. 205 (1996).

59. Hernandez, *supra* note 58, at 406.

60. See W. Levinson, et al., *Physician-Patient Communication: The Relationship with Malpractice Claims Among Primary Care Physicians and Surgeons*, 277 JAMA 553, 553 (1997).

consent involves much more than the patient signing a document, it really is a process. The signed paper is merely a way to memorialize that process. Case law has held that there is

a necessity . . . for divulgence by the physician to his patient of all information relevant to a meaningful decisional process. In many instances, to the physician, whose training and experience enable a self-satisfying evaluation, the particular treatment which should be undertaken may seem evident, but it is the prerogative of the patient, not the physician, to determine for himself the direction in which he believes his interests lie.⁶¹

Typically, when we think about informed consent, we think of a dialogue between a health care professional and the patient in which medical risks, benefits, and alternatives of a particular course of action are discussed. The patient then considers the information in the context of his, or her, needs and concerns, making a decision that is individually appropriate. Thus, the patient exercises his or her autonomy. According to the President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "informed consent is based on respect for the individual and, in particular for each individual's capacity and right both to define his or her own goals and to make choices designed to achieve those goals."⁶²

What should informed consent include when providing fertility treatment to an HIV-positive or hepatitis infected couple? First and foremost, the risks must be discussed. This will include, among other things, risks of transmission to the unaffected partner, vertical transmission to the child, complications the pregnancy may cause if the mother is HIV-positive and side effects of any medications related to the fertility treatment and/or for treatment of the underlying infection. This is also the point at which it is important to discuss the psychosocial risks including: financial burdens if the partner and/or child become infected, the potential for social stigmatization and the need to make provisions for the child if one or both of the parents is infected and becomes unable to care for the child.

The benefits must also be disclosed. These may include information about the safety of various ART techniques in reducing transmission of disease versus conception through unprotected intercourse, the availability of preconception treatments that may reduce transmission to the uninfected partner and the availability of prenatal treatment

61. *Cobbs v. Grant*, 502 P.2d 1, 9-10 (Ca. 1972).

62. TOM BEAUCHAMP & LEROY WALTERS, *CONTEMPORARY ISSUES IN BIOETHICS* 390 (Wadsworth Publishing 1982).

regimes that can reduce transmission to the child. In addition to risks and benefits, the alternatives must also be discussed. Alternatives may include remaining childless, using a sperm donor if the male partner is infected or using a traditional surrogate if the female partner is infected. Adoption may also be discussed. However, it is probably not a particularly feasible option since most agencies would be reluctant to place a child with a couple in which one or both of the partners are HIV-positive.⁶³ To adequately address all of these issues, many of which go beyond the traditional medical risks and benefits, it may be useful to involve a mental health professional, particularly when discussing issues of support, planning for the future needs of the infected partner and confronting possible societal criticism. Informed consent and ongoing communication with patients are integral in attempting to reduce the risk of liability in this highly controversial area of practice. Some commentators have recommended an approach of “contextualized counseling,” in which providers of reproductive services would engage the patient with HIV in a meaningful and informative discussion of the implications of undergoing or foregoing assisted reproduction, including the potential meaning of pregnancy and childbearing for the patient, her family, and the child who might be born. Providers would need to focus on each particular patient’s life circumstances and also on how the context of the HIV infection will impact childbearing.⁶⁴

ETHICAL CONSIDERATIONS

In addition to the legal issues involved in treating or denying fertility treatment to HIV-positive and couples with other infectious diseases, ethical quandaries are also raised. In its recent statement, the ASRM attempted to address some of these concerns, suggesting that

[i]n situations in which a child could be born with a serious disease, one can argue that individuals are not acting unethically in proceeding with reproduction if they have taken all reasonable precautions to prevent disease transmission and prepared to love and support the child, regardless of the child’s medical condition.⁶⁵

63. See, e.g., Robert Siegel, Linda Wertheimer, Stephen Smith, *All Things Considered: Couples Having Babies When One or Both Partners is Infected with the AIDS Virus*, (NPR Radio Broadcast, Sept. 7, 1999).

64. Lysterly, *supra* note 46, at 854.

65. Ethics Committee, *supra* note 21, at 220.

Few clear-cut solutions are available for resolving the ethical dilemmas raised by providing ARTs to individuals or couples infected with HIV, but balancing three guiding principles of bioethics: respect for persons, beneficence and justice may provide guidance.

Informed consent is the embodiment of respect for persons. It recognizes that with adequate information, individuals can make decisions that appropriately address their needs and interests. The meaning of beneficence is to do no harm and to maximize benefits while minimizing risks. Finally, the principle of justice is simply about treating people equally. In making the decision to treat or not treat an infected couple, balancing these three principles is important.

Respect for persons can be accomplished through the process of informed consent and subsequently respecting the patient's decision once he or she has been fully informed; beneficence and justice are not quite as evident in this context. In evaluating beneficence, one might begin by considering the view that refusing fertility services to an HIV-positive couple may be the only way to minimize risk and avoid doing harm. By denying treatment, any child born will not be exposed to HIV, nor will the female partner if she is the uninfected partner. However, what if the couple insists that if they are denied treatment they will nevertheless attempt to become pregnant by having unprotected sex? This might shift the balance. One physician stated that, [i]f you have a higher risk by ignoring it, and a lower risk by helping them, it's just about a no-brainer."⁶⁶ Dr. Mark Sauer of Columbia University echoes this sentiment stating that "Perhaps an issue of greater concern should be the potential harm created by the omission of care."⁶⁷ Their rationale suggests that denying treatment may be the course of action that actually poses more risk.

An analysis of the principle of justice might also shift the balance toward providing fertility treatment to an HIV-positive couple. If justice is about treating similar people equally, then, as one doctor commented,

If a woman and her husband both carry a Tay-Sachs gene, they have a 1 in 4 chance of having a baby with Tay-Sachs disease, a fatal genetic disorder. Even with the highest quality care,

66. Dr. Jon Pryor, *quoted in* Maura Lerner, *Newton's Apple: A Guide for How, What and Where: Helping with HIV Father Kids; High-tech Fertility Treatments are Triggering Dilemmas for Couples, Doctors*, STAR TRIB., July 21, 1999, at 1A.

67. Mark Sauer, *Providing Fertility Care to HIV-1 Serodiscordant Couples: It's Time to RE-examine Healthcare Policy*, at http://ajob-editorial.mit.edu/pin-up/download/Sauer.PDF?version_id=903 (last visited Jan. 23, 2003).

children with Tay-Sachs usually die by the age of 5. Yet, this couple would still be able to obtain infertility treatment.⁶⁸

Why should the HIV-positive couple be treated differently? The answer is not obvious given the current state of medical knowledge, therefore, denying treatment to the HIV-positive couple may not comport with the principle of justice.

The above discussion suggests only one way to analyze the ethical dimensions of the dilemma of whether to provide assisted reproductive services to those affected with HIV or with infected partners. It does favor treating an HIV-positive couple, but other factors may be considered which change the analysis. Each case will turn on its own facts and circumstances. It is important to remember that just because a particular course of action is ethical, does not necessarily mean that such activity is legal, nor is a legal action necessarily ethical.

PRACTICAL CONSIDERATIONS

While there are many ethical dilemmas and legal risks confronting those who practice in this field, it is important to acknowledge certain practical considerations. For example, with respect to the ADA, few people may be willing to file a claim due to privacy and confidentiality concerns. Individuals may not be comfortable disclosing their HIV status in a public forum. Additionally, a jury might not be as sympathetic to denying an HIV-infected person fertility services as they would be to denying the service of filling a cavity as in *Bragdon*. The added potential risks to the child may be sufficient to yield a different outcome. Another factor that must be considered is the tremendous expense of infertility services. With the average cost of IVF running approximately \$7,800 per cycle⁶⁹, it is out of reach of many individuals, and the expenses are rarely covered by insurance. Despite these practical considerations, however, the demand for fertility treatments by those affected with HIV is likely to increase as more and more infected individuals are living longer and healthier lives.

68. Howard Minkoff, *quoted in* Sue Rochman, *HIV+ Issue 10 New Right to Choose*, at <http://www.aidsinfonyc.org/hivplus/issue10/features/choose.html> (last visited Mar. 12, 2001).

69. American Society for Reproductive Medicine, *Frequently Asked Questions About Infertility*, at <http://www.asrm.org/Patients/faqs.html> (last visited Jan. 23, 2003).

CONCLUSION

Childbearing decisions are afforded the utmost privacy protection, but the advent of HIV and assisted reproductive technologies have posed challenges as to how far such protections extend. As advances in treatment for both HIV and infertility have progressed, so too have the debates regarding providing fertility assistance to enable individuals, or couples, with HIV to conceive. What has become clear, however, is that the stigma associated with HIV may have more of an impact on utilizing ART to enable couples with HIV to conceive than the medical risks.

The question of whether the ADA and its subsequent interpretation in *Bragdon* requires provision of such services remains an open one. Each case is going to have unique facts and circumstances which must be considered including; whether the male partner, female partner or both are affected, the severity of the infection, the resources available to the couple, their emotional support system, and their understanding of the risks they are undertaking. The ethical dilemmas also remain unresolved, as is often the nature of ethical debates, and exemplifies the notion that just because a particular course of action is ethical, does not necessarily mean that such activity is legal, nor is a legal action necessarily ethical.