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Robin Lynn Hardwicke

*The University of Texas Health Science Center Houston Department of Medicine and St. Hope Foundation
Associate Medical Director, fnprobin@houston.rr.com*

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The Ethics of Assisted Reproduction Technologies and the HIV Infected Woman

Robin Lynn Hardwicke, PhD, RN, FNP-C, AACRN
The University of Texas Health Science Center Houston
Department of Medicine

St. Hope Foundation
Associate Medical Director

Abstract

Currently HIV infected men and women are living longer quality lives. This phenomenon is raising more and more ethical questions concerning ability to reproduce offspring. HIV infected women frequently ask health care providers about the safety and risks of becoming pregnant. HIV infected women also face the challenges of fertility more frequently and seek assisted reproductive technologies. Each case raises many ethical questions. The case study discussed in this paper illustrates the ethical issues raised by knowingly risking the birth of a child, as well as the health of the woman infected with HIV. The paper also offers a more balanced approach to enable nurses to understand the issues.

Keywords:

Ethical Principles, Assisted Reproduction, HIV-infected Women, Infertility, Ethical Issues

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INTRODUCTION

In the United States, 25 percent of all newly acquired immune deficiency syndrome (AIDS) cases and 35 percent of human immunodeficiency virus (HIV-1) infections occur in women (CDC, 2001). Women represent the subgroup with the fastest rate of increase in HIV infection. The majority of these women are of reproductive age, and many of the risk factors linked to HIV infection (e.g., unsafe sexual activities) may also predispose women to infertility (Lindegreen, et al., 1999). Since the early years of the HIV epidemic, the treatment of infertility in HIV-infected women, as well as couples, has remained highly controversial. The possibility of mother-to-child transmission of HIV and the likelihood that the mother will die before her child reaches complete independence are among the issues faced by health care providers treating HIV positive women seeking artificial reproductive technologies (ART). The use of highly active antiretroviral therapy and protocols for the reduction of the risk of mother-to-child transmission of HIV evoke continued critical ethical considerations in the treatment of infertility in women with HIV infection.

The risk of HIV transmission to offspring can be greatly reduced but not eliminated. This risk raises ethical issues concerning the scope of freedom to reproduce (autonomy), what can be considered harm (fetal beneficence) sufficient to justify restricting that freedom, and the responsibilities (duty) of health care professionals faced with a request to provide ART services to HIV infected patients. The following is a case study to illustrate the ethical issues raised by knowingly risking the birth of a child with HIV.

Case Information

The patient is a 26-year-old female with HIV infection. She presented to an advanced practice nurse with request for assistance with infertility treatment. She reported that she has been having unprotected intercourse for 18 months without achieving pregnancy with her significant other, also HIV positive. She also reported strict adherence to her antiretroviral regimen as well as undetectable viral status for herself (<50 copies) and near undetectable viral status for her significant other (598 copies).

Past Medical History

The patient tested positive for HIV in 1999 at a local health fair offering free testing. Her CD4 count was 279/mm³ with a viral load of greater than 750,000 copies. She started taking zidovudine/ lamivudine (Combivir, GlaxoSmith Klein), one tablet twice daily and nelfinavir (Viracept, Agouron) 250mg, five tablets twice daily, to treat her HIV disease. She had an excellent virologic response to her antiretroviral regimen that resulted in a CD4 count of 525/mm³ and a viral load that was less than 400 copies within eight weeks. Menses are stated as regular by the patient. No other significant medical history was noted. No surgical history was noted.

Family History

Mother: Alive and well; hyperlipidemia, surgical menopause at age 51, G₄P₄₀₀₄

Father: Alive and well; HTN, CHF

Siblings: Alive and well; no known comorbidities

Social History

The patient has been employed as a sales clerk in a local retail store for three years. Her significant other works as a car dealer. They live together in a three-bedroom house. There is no history of injection drug use or tobacco abuse. The patient drinks alcohol on rare social occasions.

Sexual History

G₁P₁₀₀₁, menarche: age 13. First intercourse: age 15. Number of lifetime partners: 20+. Denies history of anal intercourse. Positive for history of rape at age 15 by older, known family member. Last menstrual period: 15 days ago, regular.

Current Medications

No Known Drug Allergies

Zidovudine/ lamivudine (Combivir): one tablet twice daily

Nelfinavir (Viracept): 250mg, five tablets twice daily

Multivitamin one tablet daily

Laboratory values at Initial Office Visit

HIV viral load: <50 copies/ ml

CD4+: 789/mm³

Assessment

S: 26 yo HIV+ female desiring ART

O: WNL

A: Tubal infertility

P: Should the patient be offered ART?

The Issues

A consensus is emerging that ART should be offered to some couples in which one or both partners are infected with HIV. More ethical and scientific literature states there is now an ethical obligation to provide ART to such couples, consistent with respect for both autonomy and beneficence (Anderson, 1999; Minkoff & Santoro, 2000). Those who support providing these services to this population cite three major reasons. First, therapeutic improvements in the management of HIV infection have enhanced both quality and length of life for HIV-positive individuals. Second, advances in prenatal therapy have substantially reduced the risk of mother-to-infant HIV transmission. Third, current ART methods will reduce transmission of HIV from an infected partner to an uninfected partner (Anderson; 1999, Ethics Committee of the American Society for Reproductive Medicine, 2002; Minkoff & Santoro, 2000).

Those who oppose offering ART to HIV-infected couples cite two major objections: uncertain long-term parental prognosis, and the continuing risk of maternal-to-fetal HIV transmission. The ethical underpinning of this opposition is that the best interest of the child to be born to a parent who may not be available for continuing childrearing is at stake. In addition, the risk of maternal to child transmission places the child at risk of acquiring a highly debilitating illness (Dubler & Levine, 1990).

Health care providers should keep in mind that an ethical debate supports two seemingly correct answers. Clinical ethics provide a structured approach for identifying, analyzing, and resolving both sides of the issue. The practice of good clinical health care requires a working knowledge about ethical issues, such as confidentiality, patient rights, truth telling and informed consent. It also is necessary that while philosophically studying the morality of the debate each of the issues, problems, and judgments are open for individual interpretation. This individual interpretation imposes increased difficulty in removing one's own moral issues from the debate and focusing on the debates ethical attributes. Clinical ethics relies on the certainty that, even when perplexity is great and emotions strong, health care providers, patients and their families can work constructively to identify, analyze, and resolve many of the ethical problems that appear in the clinic arena.

Practitioner Responsibilities

Prima facie duty is defined as a conditional duty always acted on unless it conflicts on a particular occasion with a more stringent duty (Arras, 1999). Today a health care provider's ethical duty is to accept a patient or to continue to care for a person who is HIV-positive and to not discriminate against those who choose to reproduce, even though it may be against the provider's moral standards (Annas, 1998). If the provider believes that in view of residual risk to the child and the mothers uncertain future, he or she does not wish to help the patient, his/her duty is to direct them to another provider who may be able to help them. The duty of the health care provider who counsels HIV positive patients is to fully inform them of the potential risks of transmission and

recommend the safest procedures for conception and delivery. This counseling includes discussion concerning administration of antiretroviral drugs to the HIV positive woman during the second and third trimesters of her pregnancy and to her baby during its first six weeks of life to limit the risk of mother-to-child HIV transmission to <1% (DHHS, 2003). Couples should also be advised that the absolute safest courses to consider are adoption, child-free living, or (if the male is HIV-positive) donor sperm.

Health care providers also have a duty to fully inform couples about risks incurred by the child such as vertical transmission of HIV from the mother, potential drug toxicities, unknown effects of drugs and/ or virus on long-term development of the child (Ethics Committee, 2002). Finally, attention must be drawn to uncertainties regarding the mother's future health due to her HIV infection. The aim is to provide full, clear and factual information enabling the couple to make an enlightened and autonomous decision.

Ethical Principles

Autonomy derives from the Greek *autos* (self) and *nomon* (rule or governance) and literally means self-rule (Pickett, 2001). In health care practice, the principle of autonomy implies personal rule of the self that is free both from controlling interferences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding (Beauchamp & Childress, 2001). Respect for a patient's autonomy acknowledges a person's right to hold views, to make choices, and to take actions based on personal values and beliefs. Couples who are at risk for having other potentially life-threatening conditions that may affect them physically by conceiving or affect the outcome of the unborn child are not as scrutinized as HIV positive individuals. Treatment for ART is offered to other individuals with other illnesses such as cancer or heart disease or brittle diabetics. People who have genetic illnesses or who are at high risk for producing offspring with genetic illnesses are not condemned for the choice of parenthood. The right for reproductive choice comes from the principle of autonomy, whereas bringing about the birth of a child with a genetic disease has been considered as causing harm by some (Macer, 1990). Couples do not forego parenthood only because they are at high risk for producing a child that will have sickle cell disease, Down Syndrome, or cystic fibrosis, for example. Couples who conceive naturally do not have to justify their desire to have children. Maternal age is another risk factor that places offspring at risk although in most cases is overlooked by society. Being HIV positive does not mean that having an ill child is any worse than couples having an ill child from cystic fibrosis, sickle cell, or Down Syndrome. Unless however, the health care provider or society is allowing morality to overcome ethics. Autonomy provides a strong moral foundation for informed consent, in which a patient, fully informed about her medical condition and the available therapies, freely chooses to be a willing participant in any treatment or non-treatment (Mappes, 2001). Respect for patient autonomy, like all ethical principles, cannot be regarded as absolute and may at times be in conflict with other principles or other moral considerations. This health care

providers regards must allow for the patients autonomy and decision to conceive a child and reach a balance with fetal beneficence.

Beneficence, which means doing or producing good, is the obligation to promote the well-being of others (Pickett, 2001). In this case, the fetus must be considered in regard to the ethical principle of beneficence. Although the risk of vertical transmission of HIV infection from mother-to-child can be reduced in many ways, the risk cannot be completely avoided. Health care providers who evaluate the ethics of assisting such patients to have children must address the question of whether offspring born with HIV are harmed despite the preventive steps taken. The health care providers and parents must consider the child may be born with HIV. In 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 all reasonable precautions are taken to prevent disease transmission. Similarly, one can argue that health care providers are not acting unethically if all reasonable precautions to limit the risk of transmission of HIV are taken. However, health care providers cannot ethically proceed with ART if the facilities lack the clinical and laboratory resources needed to effectively care for HIV-positive couples that wish to have a child (Ethics Committee, 2002). In such instances, the health care provider should refer couples to a center that has these resources.

Finally, justice is the principle of rendering what is due to others (Pickett, 2001). Justice is the most complex of the ethical principles to be considered because justice deals with the health care provider's obligation to render to a patient what is owed and with the provider's role in the allocation of limited medical resources in the community. Justice is the obligation to treat equally those who are alike or similar according to whatever criteria are selected. The issue of justice raised in this case is similar in some respects to those in couples who know they are carriers of an autosomal recessive disease, such as sickle cell anemia, Tay-Sachs disease or cystic fibrosis. The risk of transmitting an autosomal recessive genetic disease cannot be reduced below 25 percent, whereas the risk of HIV transmission can be reduced to as low as <1 percent (Lindegreen, et al., 1999). Health care providers who are willing to provide ART to couples whose offspring are irreducibly at risk for a serious genetic disease should find it ethically acceptable to treat HIV-positive individuals who are willing to take reasonable steps to minimize the risks of transmission.

Case Review

In this case, the advanced practice nurse examined her own moral regards and chose to be guided by ethical principles, thus choosing to assist the patient and continue further care as part of her duty. Information was provided to completely inform the patient of all risks of pregnancy and HIV, as well as all options of ART. Time was offered to the patient to allow for autonomy in decision-making. This patient reported complete adherence to taking her antiretroviral medication regimen. Her laboratory results indicated viral control (VL < 50 copies), as well as a healthy immune system (CD4+ 789/mm³). These values infer minimal (<1percent) risk of viral transmission from

mother-to-child as well as decreased risk for infection to the mother. Fortunately, a balance of patient autonomy and fetal beneficence could be established in this case. Based on the information provided to reduce viral transmission risks and allow for the promotion of fetal beneficence, as well as mother beneficence, the patient was allowed and capable of being autonomous in the decision making process of her pregnancy and care. The patient was then referred to an obstetrician who specializes in assisted reproduction.

Conclusion

Requests for ART by HIV-infected couples will most probably increase in the future. The consortium of infected individuals with stable illness and with or without infertility is growing. These individuals are becoming aware of the low risk of maternal-to-infant HIV transmission with appropriate treatment and are desirous of attempting to achieve pregnancy.

Assisted reproductive technologies should not be denied to HIV-infected individuals solely on the basis of their positive serostatus. Offering these technologies to infected individuals is consistent with balancing respect for autonomy with fetal beneficence. This field is an emerging one and is changing rapidly. Patients should be cared for by providers who have current knowledge and expertise in this field. For this reason, nurses as well as other health care providers, need to educate themselves with the ethical considerations, the technologies involved, and the accompanying knowledge base needed to advocate for these patients.

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Author Contact Information:

Robin Hardwicke, PhD, RN, FNP-C, AACRN

The University of Texas Health Science Center- Houston
Assistant Professor, Department of Medicine

St. Hope Foundation
Associate Medical Director

6800 West Loop South, Ste. 560
Bellaire, TX 77401

Phone: (713) 839-7111

Fax: (713) 839-7156

Email: Robin.L.Hardwicke@uth.tmc.edu

Corresponding and Reprint Requests:

Robin Hardwicke PhD, RN, FNP-C, AACRN

Home Address:
5707 McKnight Street
Houston, TX 77035

Phone: 713-728-2342

Fax: 832-689-6268

Email: fnprobin@houston.rr.com