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# **WOMEN REPRODUCING IN THE TIME OF HIV**

by  
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**November 30, 1992**

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Openness to life grants a lightning-swift insight into the life situations of others. What is necessary?--to wrestle with your problem until its emotional discomfort is clearly conceived in an intellectual form--and then act accordingly. (Hammarskjold 1964).

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## **INTRODUCTION**

I have been involved in the field of HIV since 1986, notifying and counseling blood donors who were found positive for Human Immuno-deficiency Virus (HIV). Presently I am counseling heterosexual couples where one or both partners are infected with the HIV virus, the virus that causes Acquired Immune Deficiency Syndrome (AIDS).

### **DESCRIPTION OF THE PROBLEM**

From the time transmission of HIV from mother to child was first recognized as a possibility in 1984, physicians and public health officials recommended that women who are HIV positive forego having children. If they learn they are HIV positive in the first or second trimester of their pregnancy, they are frequently told that they should seek an abortion. Those who are able to choose that option are often refused services because they require "special treatment" that is "not available" at that particular clinic. In fact, the only instances when such women actually require "special treatment" is when a woman is in the advanced stages of HIV disease and is extremely vulnerable to infection, or when a special medical condition exists, such as a very low platelet count that would warrant

monitoring to avoid excessive bleeding. Those women who do not choose abortion are often subject to extreme pressure to do so or harsh criticism, and refusal by the physician to provide them with pre-natal and obstetrical care. Thus, many women do not disclose their HIV status, which may compromise the quality of care that both the woman and her baby are to receive. (1)

Some HIV negative woman whose partners/husbands are infected, and want to have a baby and do not want to expose themselves or the child to infection, have chosen artificial insemination by donor (AID) as an alternative. Some have had physicians refuse to assist them in obtaining AID when they disclose their husbands' status.

One of the couples in our study chose the route of adoption as an alternative. They did not disclose the HIV infection of the positive partner. Because it was very early in the epidemic when heterosexual couples were not being considered at risk for HIV, no questions about HIV were raised. Recently a couple making an anonymous call to an adoption agency, inquired about the agency's policy regarding granting a couple a child if one partner is HIV-infected. They were immediately put on hold and transferred to a supervisor. The official response from the supervisor was that a couple would not be *automatically* excluded if a partner was HIV-infected. The fact that such a question was referred to someone in authority leads me to believe that this question has not been raised or that a uniform policy has not been adopted. I would anticipate, given the stringent guidelines for adoption already in place, that HIV would greatly impact on the couples eligibility for adopting a child.

For the purposes of this paper, I will focus on the HIV positive woman who wants to have a baby. This is usually the circumstance in which the strongest reaction from the health professional and the public sector is heard. Certainly this is not intended to ignore the ethical dilemma that exists when a HIV-infected man wants to have a baby with his negative partner, who may or may not have knowledge of his status. For the sake of justice, and respecting the magnitude of these dilemmas, a separate analysis should be initiated.

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## **OUTLINE OF THIS PAPER**

**Chapter One** discusses the role of parenting, both natural and adoptive, reflecting the differences and highlighting the prima facie right of the natural parenting process. With the onset and rising statistics of perinatal transmission of HIV from mother to infant this natural right is being threatened. The implicit imposing of adoptive parenthood guidelines on HIV-infected women are explored. Along with this the privacy of reproductive decision making is explored in the context of HIV. Is the threat of HIV perinatal transmission sufficient enough to invade that privacy?

There are so many issues in this dilemma, that there is a need to separate them in order to begin to be objective and to focus clearly on these issues? What is a family today? How

does an HIV-infected woman fit into that description of family? What does this woman look like? Can she be rational in her desire to have a baby? Is she responsible enough to care for this baby?

**Chapter Two** addresses, in depth, the epidemiology of HIV infection and AIDS in both women and children. It includes the natural history of this disease in women, the impact of HIV-infection for both mother and baby, the pathophysiology of vertical transmission, the differences and difficulties in diagnosing HIV infection in the newborn as compared to diagnosing in the mother, along with a brief overview of the clinical management of the HIV-infected woman, including one who is pregnant woman, and the child of such a woman.

At this point in the epidemic, though there still remains a great deal to learn about transmission of the virus from the mother to the fetus, a great deal more is known than ten years ago. Studies show that there is approximately a 30% chance of transmitting the virus from mother to fetus, which is significantly different from the original 100% transmission rate hypothesized at the onset of this epidemic. There is evidence that the stage of disease in the mother is a contributing factor for transmission to the fetus.

There are drug trials effectiveness of taking transmission presently underway evaluating the drug AZT in preventing vertical transmission.

**Chapter Three** discusses that despite all of these variables regarding transmission from mother to child, most health professionals react quite emotionally, adamantly refusing to recognize any circumstances in which it would be acceptable for a seropositive woman to become pregnant. Are these reactions rational? Do we have history of a similar reaction to a dilemma that would clarify this present one?

Is this reaction so strong because it has ramifications not only to the mother, but to the fetus as well? With continuing advances in knowledge of fetal development over the last two decades and the increasing knowledge of the impact of maternal behavior on the fetus, there are ever increasing conflicts between the rights of the mother and the rights of the fetus (Coutts 1990). Are women's right to privacy and autonomy overridden by the rights of the fetus, regardless of the fact that without a biological mother, a fetus can not exist.

Are the objections valid that the baby who is born of an HIV infected woman would not have a life worth living (Feinberg 1988)? Or is it a "concern for the potential social costs that would be incurred by the care of HIV-infected babies (that) has contributed to the sense of urgency (Bayer 1990)?"

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## **CHAPTER ONE**

### **THE RIGHT TO HAVE CHILDREN**

It is presumed in modern liberal societies that people have a right to do what they want to do, unless there is a specific moral or legal objection to the act. Historically in the United States, women have had a prima facie right to have a child. For the past two decades women have medically, with the advent of oral contraceptives, and legally, through Roe vs Wade, made historical gains toward possessing the right of and control over their own reproductive choice. There are now two powerful conflicting political forces which jeopardize that control. One force is the pronatalist movement which seeks to compel pregnant women to yield their rights to the needs of the fetus, along with the pro-life movement, that would rescind Roe vs Wade based on their belief that abortion is immoral because it is murder. The other force is the public health authorities, who recommend forgoing childbearing by those women who are HIV-infected. This recommendation has not only been adopted by many health professionals, but amended with a strong directive and a sometimes aggressive recommendation for a woman to abort if she is pregnant and not to have a baby if she is HIV infected. In addition, the pro-choice movement sees the HIV reproduction issue as an assault and possible threat to their hard earned gains. Despite the decline in estimates of perinatal transmission from 100% to 30%, the same recommendations to forgo having children are in effect, in fact have gained momentum, along with popular appeal. When the question of reproductive rights of HIV infected women is raised in the context of a casual conversation, the IMMEDIATE response, devoid of any deliberation, and full of emotion, is an overwhelming !! NO !! This has been a response from the general population, as well as from physicians and academia. Are women who are HIV-infected different from others in their wish to become a parent? Does their HIV-infection make their wish to have children irrational and/or immoral? Will the HIV epidemic threaten the prima facie right of women to have children? Will the burden of proof shift from the state rescinding her right to bear a child to the HIV-infected women having to prove her right to reproduce? I believe that those who oppose child bearing by HIV-infected women are trying to impose the standards of adoptive parenthood onto a natural mother. It is the goal of this paper to discuss this issue that seems implicit in the recommendation that HIV-infected women "forgo" having children.

## **TYPES OF PARENTS**

In the context of HIV, is it possible that much of the emotion brought to bear is buried within the preconceived image that each of us have when picturing an HIV-infected woman or couple, and how that alters our interpretation of their ability to be a mother or parent?

There are different types of parents. When one traditionally thinks of a parent, a "natural parent" or "biological parent" comes to mind, that is both parents have contributed their own genetic material to conceive their baby, and that the natural mother carries to term and delivers their baby. Over the last ten years, because of the scientific advances in the field of reproduction, many possible variations of the above theme have developed, whereby a child can be conceived with three or four sets of "parents".

For the purposes of this paper, and to maintain clarity, when the term biological parents is used it will refer to the traditional one. To become a parent in this fashion does not

require any legal steps. If the parents are married to each other both the mother and the father are recognized as the parents of their baby and acquire the rights and responsibilities of parenthood. What these are will be discussed later.

Another type of parent is the adoptive parent. Generally in this country, adoption exists only by virtue of statute, and is not considered a natural right. One does not have a prima facie right to become adoptive parents. The state has the right and power to determine who may be the recipient of the privilege of adoption of one of its wards. It may extend or deny this right to couples or individuals after assessing the existence or lack thereof of certain qualifications of those who want the opportunity to adopt and rear a child of their own. To adopt a child is not an easy process and the degree of difficulty in adopting reflects the importance we, as a country, state and community place upon this act. Prospective adopters are interviewed many times both in the offices of the adoption agency and are visited at their home by a social worker to assess the environment that the adoptee may live in. Both prospective parents agree to relinquish their privacy during this process and allow the agency to look into their social, financial, educational, professional, and religious or moral background. This process is usually a lengthy one, taking months or possibly a year. Similarly, a state may declare who is a candidate for adoption (Herbenick 1979).

## **ADOPTIVE PARENTS**

Those who come to the adoption process arrive from various routes. Most have tried unsuccessfully to become natural parents and have chosen to adopt. Some have undergone years of medical intervention with those physicians who specialize in fertility problems. As a rule, they have spent thousands to tens of thousands in this attempt to have a natural child. For some couples such emotional and financial stress results in divorce or so close to it that they must seek the adoption alternative in an effort to have a child and maintain an intact marriage. Others have come to their union knowing that one of the partners is unable to impregnate or conceive a baby. Still others feel that the world is overpopulated, there are so many children who have no parents that adoption is a method to have a child and to not further increase the world population.

We know that today many people who become a family, either through the natural or adoption process, are not part of a couple and not necessarily heterosexual. This change has been gradual over time and has helped revolutionize the definition of family. The family as defined by Carol Levine (1990):

Families should be broadly defined to include, besides the traditional biological relationships, those committed relationships between individuals which fulfill the function of family.

Another way of looking at these individuals/couples is to see that they very much want to become parents, are highly motivated, and have "labored", so to speak, socially, financially and emotionally for a sustained period, often years, to achieve their goal.

## NATURAL PARENTS

People come to the role of natural parents from many different routes. There are those who have lived together for years before committing themselves to common law, cohabitation, union or marriage and only after a time that they both think is sufficient enough for them to be reasonably secure that their marriage will last, do they proceed to become parents. Certainly, their mutual desire to have a child or children has been discussed well in advance of their commitment to each other. They have shared their own individual philosophies about childrearing, the role of each parent, their own professional lives and future aspirations and how parenthood would impact on both of their careers. They have looked at their own financial capabilities and feel reasonably satisfied they will be able to afford the financial responsibilities having a child invokes.

Still others have not put such forethought into making a decision about being parents. They, like many of us, have gotten a message that to be a parent is as "natural" as being born. It is a very essential right to be exercised by all. This message has been reinforced in so many ways and so thoroughly, that to merely consider not having a child usually places one in a very stressful and conflicted state, wondering what is wrong with oneself. A majority consciously do not put much consideration into becoming parents. They look upon parenting as a dream come true, and that whatever is necessary to become parents will come to them as naturally as the physical act that leads to conception.

There are those who become married because they are going to have a child. They may not have put much time, thought, and preparation into the conception of this baby. The marriage at best, is premature, with a period of adjustment for the couple that is complicated by the physiological and emotional demands that pregnancy places on the parents. The child may be seen as an unplanned burden rather than a much awaited culmination of planning and preparation.

Still there are others who may or may not be couples, or couples who may or may not be committed or married to each other, who find themselves with an unwanted pregnancy. Having a child was definitely not a part of either or both partners plans. The pregnancy was merely a result of having sexual intercourse without any method of contraception or with a method of contraception that failed.

There are an increasing number of women and some men who are heterosexual and not coupled that have put much thought and planning into their decision to have a child and become single parents. This is achieved by women more easily than by men, but still entails a definite plan that reflects deliberation as well as determination.

There are also both gay men and lesbian women who have decided to become natural parents. Their sexual orientation presented a challenge which provoked much thought, planning and forethought, not only with their life partner if they were coupled, but also with whomever they chose to be the natural parent of their child, taking into consideration whatever partner situation that person is committed to. The coordination of agreement among these diverse sets of parents certainly represents a preponderance of

motivation, along with herculean cooperation resulting in the birth of a child with a natural set of parents and possibly one or two more "stepparents".

There are other situations leading to becoming a natural parent that have not been covered here. None of the those that have been described above, require the state's assessment, investigation or permission to occur.

## **THE HIV POSITIVE WOMAN**

As Chapter Two will review the epidemiology of HIV infection in women in the United States in more detail, I would like to focus on the more personal portrait of this woman in this section. Extrapolating from those statistics on women who are diagnosed with AIDS, and looking at one hundred women who are HIV-infected: 84% will range in age from 13-49, 74% will be women of color, 26% will be white, 51% will have a history (past or present) of injection drug use (2) and the majority of these women will live in larger East Coast urban areas. This results in a picture of a disadvantaged woman, likely to be African-American or from the Latino culture. She will have experienced overt and covert discrimination as a woman and as a woman of color throughout her life. This will occur in her early family life experiences, health care experiences, (as early as in utero), educational experiences and opportunities, including the subtle and not so subtle political and religious philosophies that she will be educated in, and will have a profound affect on her own professional expectations and training. Much of this discrimination will be reinforced by her own culture as well from the public sector.

This picture is brutally complicated when addiction is added. It is also becoming evident that the portrait of a seropositive woman is one in which physical or sexual abuse as a child by a substance abusing parent(s) and/or as an adult by a substance abusing partner(s) is frequently part of her history (Zierler 1991).

Many of them, if the pregnancy is brought to fruition, will be single parents, many of their choosing, some not, and most far away from the single parent ideal that was mentioned earlier. One merely has to look at the restrictions on federally funded abortion clinics to see that poor women do not have a wide variety of options to choose from if they find themselves pregnant. They certainly enter the health care system as well as the public sector burdened with the prejudice that this society has against the poor and disadvantaged groups, women in general, and women of color in particular (Levine and Dubler 1990).

Although most people have this picture etched in their mind when they think of an HIV-infected woman, the above picture is not as accurate as it once was. The present picture is quickly changing due to the latency period of this disease before symptom manifestation, the reluctance of many health professionals to accept that other than poor women of color are getting infected, and the fact that 65% of all American women who die of AIDS go undiagnosed until the time of their death. This picture is undergoing revisions, as the epidemic not only is rising at an alarming rate among women more than any other category, but it is also moving across all socioeconomic and ethnic boundaries.



The HIV infected women that qualify for our study of transmission cofactors in HIV+ heterosexual couples are in an ongoing relationship/marriage with their partner. (3) The majority of their partners are negative and they are aware of their partners positive serostatus. These women have levels of education that range from no high school education to a doctorate level or professional degrees.

The risk behavior that led to infection is either past sharing of drug injection equipment, or for the majority, heterosexually transmitted from a man who was (unknowingly) infected. We see White, African-American, and Latino women in that order. Part of this diverse cohort of women were recruited from blood donors who were notified of their serostatus about one month following their donating blood. Presently, we are enrolling participants from a variety of sources that continue to give us a heterogenous population. Many couples are self-referred from publications such as Body Positive, a newspaper for people who are HIV-infected, or newspaper ads, some are from infectious disease (ID) clinics of hospitals in the greater metropolitan area, from alternative testing sites throughout the five boroughs, or from the "snowball effect", word of mouth from people who belong to a variety of support groups addressing either HIV issues or issues surrounding recovery from addiction, and often times both.

## **OBLIGATIONS OF PARENTS**

To drive a car, you must be able to demonstrate that you have a working knowledge of the steps to enable your car to proceed in traffic in a safe way and are aware of the rules of the road and adhere to them to further your safety and of those who share the road with you. When you acquire these skills and pass a written test, a vision test and a road test, you are given a license which gives you the legal right to drive. Endless types of licenses exist and the skills and knowledge that are required are to a more or lessor degree correlated to the degree of difficulty in being proficient in those skills. To become licensed as a teacher requires a minimum of a bachelors degree, and depending on what level of education you would like to participate in, a PhD may be required. To become a health care worker, depending on what discipline you seek, requires both educational and clinical skills that are addressed in a licensing exam. Different states may require different levels of proficiency to acquire a license with them. When you organize a street fair, a permit must be obtained to hold that fair, to block out traffic and devise an alternative traffic pattern, to provide some type of security as it relates to crowd control depending on the numbers of visitors expected, etc. Nowhere is it stated that you do not have a right to pursue driving, teaching, a helping profession, or hold public assembly. Most people who acquire the necessary education and skills to meet the standards of licensure, along with those who will be recipients of those skills would not say that their rights are being taken away. In fact, they would probably agree that their rights to an education, good health care, safe transportation and safe assembly are being protected.

Another type of license that many acquire in their lifetimes is that of a marriage license. Despite the fact that it represents a legally binding commitment, along with any religious beliefs and promises that often times override the legal aspects and raise it to the level of a religious sacrament, a marriage license is very easily obtained and involves no skills

nor education. It is no longer necessary to take a blood test for syphilis in New York State. You simply go to your local marriage license bureau, fill out a simple demographic questionnaire, pay a very nominal fee and you have met the requirements for obtaining a marriage license. The only restriction that applies is that of a twenty-four hour waiting period before the license is valid.

"We deal with a right of privacy older than the Bill of Rights-older than our political parties, older than our school system. Marriage is a coming together for better or for worse, hopefully enduring, and intimate to the degree of being sacred. It is an association that promotes a way of life, not causes; a harmony in living, not political faiths; a bilateral loyalty, not commercial or social projects." [\(a\)](#)

[\(a\)](#) Griswold V. Connecticut 381 US 479, 486, 14 L Ed 2nd 510, 85S Ct 1678 (1965).

It seems there is a contradiction here, the acquiring of a marriage license is really just a legal formality even though most citizens look upon the state of matrimony as one of the most important life decisions they will make. As of this writing, it has not become legal for gay men or lesbian women to be married, although they are being recognized by some churches and certainly a wider range of the community. [\(4\)](#)

The degree of difficulty in acquiring a marriage license certainly does not correlate with the skill required to be successful in a marriage, and is reflected in the high divorce rate.

What society is saying by mandating various license requirements is that we have the right to limit people when they are operating in the public sphere. Some would argue that there is a difference between driving a car and having a baby. The driver has an ability to inflict injury out in the public sphere, and we have the right to limit how people behave in the public sphere. Domestic life is in the private sphere, and no stranger will be hurt by a baby. Likewise, we require licenses for doctors, because they practice in the public sphere and we have the right to expect that they will meet certain standards of behavior. Babies do not exist in the same sphere, and we have no right to expect a baby to behave in any particular way.

While the above argument is valid and I strongly agree with the thesis that there is a difference between driving a car and having a baby, it skips over two very important points. One is that a baby will undoubtedly, if the child lives, enter into the public sphere as a citizen when adulthood is reached. Secondly, it does not speak to the process of parenting, which is a privilege and an obligation that can not be surpassed in its ultimate impact on our future, both public and private. Why is there such moral discrepancy between becoming natural parents and becoming adoptive parents? Will this epidemic generate a more responsible parent, bringing a just balance between right and obligation? Or will this epidemic generate a climate in which the right of natural parenting undergoes restrictions?

The goal of this paper is not to bring the public sector into the private act of parenting. In fact, because of this HIV epidemic, we must guard against any infringement on the prima facie rights of women to have children. The climate is such that many different forces are at work to bring about such an infringement, and would use this epidemic, and the emotions that come to it, toward the achieving of their sometimes conflicting goals of eugenics, racial discrimination, and the rescinding of women's right to choose. However, it is important to note that we as a society have given its citizens an unconscious but powerful double message about parenting. Looking at natural parenting we seem to be saying that one does not need any permission, education, or skills to become a parent. However, those who try to become parents through the adoption process, are given a message through its rigorous eligibility requirements, that being a parent is a most important step requiring financial, emotional, and social stability that not just anyone can provide. Might we not preserve the basic rights of natural parenting while elevating the obligations of that role?

## **THE PRIVACY OF REPRODUCTIVE DECISIONS**

Because general negative rights are rights of noninterference, their direct connection to liberal individualism is apparent, with its typical emphasis on freedom from government and protection of zones of privacy (Beauchamp and Childress 1989).

Privacy is based on rights of liberty and property and derived from the "right to enjoy life--the right to be let alone" as stated by Warren and Brandeis in 1890. This concept of the right to privacy has evolved over time. Currently we often see the concept of autonomy to convey the right to privacy.

Personal autonomy carries over the idea of having a domain or territory of sovereignty for the self and a right to protect it--an idea closely linked to the ideas of privacy and the right to privacy. The personal domain includes its spatial dimensions--the person's body (Beauchamp and Childress 1989).

Along with the right to liberty, the right to privacy has been expanded to include women's freedom over her own reproductive processes. This right to privacy has been used to argue for a woman's right to have an abortion, calling for the recognition of a woman's ownership and ultimate control over her own body. This recognition should include all of a woman's reproductive processes, the right to decide to have a child as well as the right to decide not to have a child. The more options that science and medicine give to us to change and control various biological functions, the more we must be aware of maintaining a balance between justice and progress. Are we in danger of using abortion eugenically, not considering or overriding, the basic right of liberty and privacy? Historically, our society has not only recognized, but cherished the non-public value of family life. In light of perinatal transmission, there are public health concerns that we must consider. But do we do this by rescinding a woman's right to liberty and freedom. Are we as a society now willing to invade a woman's right to privacy? Are we ready to invade the sacred zone of family?

## THE HIV-INFECTED WOMAN WHO WANTS TO HAVE A CHILD

We have come full circle and arrived again to the seropositive woman who wants to have a baby. How does she fit into the above descriptions of different types of parents? These have included the conventional picture of a heterosexual couple who are married and are becoming natural parents. On the continuum, there are different types of single parents; those who have made an informed and well planned decision, and those who have no plan, and the responsibility of raising that child is usually born by the mother, if she maintains custody.

In addition to being HIV-infected, is she currently abusing substances? Does she herself come from a history of parental deprivation, neglect, or abuse? If so, how has this impacted on her emotional stability and her ability to provide the nurturing that is necessary as a parent? Is she financially able to provide the basics for her baby? What is her health status? How far along the HIV spectrum of disease is she? Has she progressed along the continuum to be more than a 30% risk of transmitting the virus to her fetus? What is her prognosis for surviving X number of years? Does she have a support system that would help her with her child in the event of illness or death?

Even though all of these questions are pertinent, how many of them are addressed by women who are not HIV-infected? Theoretically, one would hope that some of them are considered. Of course, this is far from the case as has been shown while discussing the natural parenting process. However the one issue that is probably not considered by most uninfected women in our society, is that the mother may not live to see her child grown, due to any number of catastrophic events.

To address the problem realistically, a woman who is HIV-infected does not fit into the "norm". She has a virus, that at this particular point in time, with our current knowledge and experience, is terminal. She brings with her desire to have a baby a need for "special treatment" as is the case when a woman has a genetic trait that she may give to her baby, or a woman that has a terminal disease. Does her serostatus, along with her desire to have a baby, warrant the immediate dissenting response that she has been met with? Should she immediately be stripped of her rights to liberty and privacy as it relates to her reproductive freedom? Or could there be circumstances where it would be acceptable for her to have a baby? Is there ever a condition when giving birth would violate the rights of the newborn? Individual rights respected, should we consider, will the happiness of the world be increased or decreased by this woman giving birth?

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## NOTES [CHAP 1]

1 When a HIV positive woman is seeking gynecological care, she is often refused treatment by the physician if she discloses her HIV infection.

Seropositive women are much more likely to develop gynecological problems such as pelvic inflammatory disease (PID), abnormal pap smears showing the presence of cervical dysplasia, and Human Papilloma Virus, (HPV) a cofactor in cervical cancer (Clinical Courier 1991).

2 However, heterosexual transmission accounted for the fastest growing segment of AIDS cases, with a greater than 30% increase from 1989 to 1990 (Clinical Courier 1991).

3 We also have another cohort of HIV+ women who may or may not be part of a couple, or if they are, either partner is not interested in joining, or do not meet the eligibility criteria of that study. These women are also diverse, but the majority are white and self-select to acquire the intensive gynecological exam that is often lacking in the private sector. The study is examining the incidence of cervical dysplasia/cancer in seropositive women, so these women know that their serostatus will not be a stumbling block for them.

4 Homosexual couples, however, have recently made some gains as far as obtaining some of the rights given to heterosexual unions. This came about as the result of the AIDS epidemic when one partner would lose everything when his partner died. All property and financial interests would be taken over by the family of the deceased totally negating the rights of the survivor. There are now in place legal documents that protect and recognize their union.

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## **CHAPTER TWO**

In this chapter we will look at the epidemiology of HIV infection and AIDS in both women and children. We will follow the natural history of this disease in women, the impact of HIV-infection for both mother and baby, pathophysiology of vertical transmission, the differences and difficulties in diagnosing HIV infection in the newborn as compared to diagnosing in the mother. We will finish with a brief overview of the management of the HIV-infected woman, pregnant woman, and child.

### **EPIDEMIOLOGY OF HIV INFECTION AND AIDS IN WOMEN AND CHILDREN**

As of August 1991, 191,601 cases of AIDS were reported, including 19,281 cases in women and 3,253 cases in children under 13 years old (CDC 1991). It is now approximated that between 1 million and 1.5 million persons in the United States are HIV-infected (Modlin and Saah 1991). Homosexual men were the first reported to be infected with the HIV virus, followed by hemophiliacs. [\(1\)](#)

Before 1985, when there was no test to detect the presence of HIV antibodies in blood donors, the receiving of contaminated blood or blood products was a significant mode of transmission to adults and children. Since the introduction of the Elisa and the Western Blot to detect the presence of HIV antibodies in blood donors, the major mode of transmission to children is vertical transmission in which an HIV-infected mother transmits the virus to her baby sometime during gestation or during the birthing process. These numbers exclude the much debated attempt to revise the CDC definition of AIDS to include anyone with T Helper cells of less than 200. [\(2\)](#)

It is important to note that these numbers reflect CDC AIDS defining diagnosis. They do not reflect the numbers of women and children who are HIV-infected, who do not yet have AIDS and more importantly those that are unaware of their HIV infection. It is estimated that those women diagnosed with AIDS reflects approximately 20% of those that are HIV-infected. It is estimated that 2-3 times the number of children with AIDS are HIV-infected. It is projected that by the year 2000 the number of women with HIV infection in the United States will equal that of men (Modlin and Saah 1991). Calculating an average of 10 years from infection to AIDS diagnosis, by 2092 there will be approximately 27,285 number of women and 9,759 children with AIDS. Also noteworthy is that this forecast does not take into consideration the as yet unknown numbers of

adolescents that are HIV-infected and how that population will affect the future of this epidemic. (3) In the past HIV infection in women and vertical transmission of HIV to children have both been primarily associated with intravenous drug use (IVDU) past or present (Guinan and Hardy 1987). Recently there is an increase in the number of cases reported of woman who are not themselves IVDU, but are becoming infected by sexual contact with a male partner who is, or had a history of IVDU. (4)

Historically, drug addiction has affected the disadvantaged and is concentrated in African-American and Latino populations. Both of these populations are over represented in the number of AIDS cases reported when compared proportionally with their population size (Modlin and Saah 1991). This disease is being seen as an epidemic isolated to particular groups; homosexuals, the IVDU population in general, and among the African-American and Latino population in particular.

All of these populations are certainly stigmatized, which adds to the "us and them" denial in the remainder of the population. Looking at the routes of transmission that are universal to this epidemic (5), both here in the United States and worldwide, the above demographics will change dramatically within the next 10 years in the direction of increasing HIV infection in women and children. (6)

## **NATURAL HISTORY OF HIV DISEASE IN WOMEN**

Heterosexual Transmission not related to IVDU and sexual contacts with men who are HIV-infected due to IVDU, is also on the rise. Approximately 84% of women with AIDS in the United States are of childbearing age (CDC 1991). In addition to the social controversy whether heterosexual transmission even exists, (7) there is another widely debated question as to the gender specific transmission efficiency of the HIV virus. Recent studies have clarified some of the heterosexual transmission factors. It has been reported in one study in Europe that the suggested transmission rate from male to female is 1.9 times more efficient than female to male transmission. It is important to note that this study excluded partners reporting risk factors other than sexual contacts with the index patient. (8) Of the 563 couples, 9% of the men and 27% of the women, heterosexual contact was identified as the mode of infection of the index case (Vincenzi 1992). The conclusion of this preliminary study is that the number of women infected through heterosexual contact could potentially be double that of men and certainly will form an increasing fraction of the total HIV population. That has tremendous ramification for the future of women in general, women of childbearing age in particular, the gender distribution of AIDS and on worldwide population in the future if there is not, at the very least, a dramatic reduction of newly HIV-infected persons.

## **IMPACT OF HIV INFECTION ON WOMEN AND EXPECTANT MOTHERS**

There is very little known about the natural history of HIV infection in women in general, and about any differences which may result from different modes of infection. Most of the data on the natural history of HIV infection in adults have been obtained from cohort

studies of homosexual males (Lui 1988) and of male hemophiliacs (Jason 1989). In 1988, among the homosexual population, the median time from infection to the development of AIDS was estimated to be 8-11 years. This remained relatively constant for the hemophilia patients when the data was adjusted for duration of HIV infection (Modlin and Saah 1991).

It is expected that by the year 2000 the number of women with HIV infection in the United States will equal that of men. Heterosexual contact is now the fastest growing segment of HIV transmission in America with a greater than 30% increase from 1989 to 1990 (Clinical Courier 1991). As with other diseases, gender differences in disease manifestations are likely to occur. Women may also exhibit HIV infection in somewhat different ways as the disease progresses. The following are potential indicators of HIV infection in women: gynecologic infections (changes in severity, frequency and resistance to therapy), Human Papilloma virus (HPV) (precursor to cervical cancer), genital ulcers, cervical dysplasia and genital warts (HPV), along with opportunistic infections (OIs), pneumonia, and sepsis (Clinical Courier 1991). [\(9\)](#)

Pregnancy may alter the HIV-infected women's immune response. At present there is insufficient data on the effect of HIV on a pregnant woman, nor are the potential results of pregnancy on the natural course of HIV infection understood. Many other variables that are likely to effect the outcome of a pregnancy in addition to HIV infection such as access to care and treatment, drug, alcohol, and tobacco use, nutritional status, education, and socioeconomic status. It will be critically important to study and control for these other risk factors to determine the role of HIV. Several investigators have hypothesized that once these other factors are controlled for, the additional burden of HIV infection will not adversely affect the pregnancy outcome to a significant degree, other than placing the infant at risk for HIV infection via vertical transmission. Looking at the other issue for women, whether or not HIV infection during pregnancy becomes a more aggressive disease, is altogether another complex matter that will be addressed later (Repke and Johnson 1991).

## **HIV INFECTION IN INFANTS**

The impact of HIV infection on an infant has a varied picture. For the most part, all HIV-infected infants appear normal at birth. However, a prospective study has revealed that within the first 12 months of life, 60% will develop clinical signs, and 75% will become symptomatic by 2 years of age. This equates to a median of 9-10 months for the development of clinical signs with some infants presenting symptoms within 2 months of life, while others live for more than 7 years without symptoms. By 18 months, 25% developed an AIDS-defining illness such as an opportunistic infection, lymphoid interstitial pneumonia (LIP), recurrent bacterial infections, or neurological disease. By 43 months, 50% experienced such an event.

Survival time in these children varies. Infants presenting with an AIDS-defining illness in the first months of life have a poor prognosis, with an expected survival of less than a year; those who have a later onset may have a natural history closely following that of



adults with HIV infection (Krasinski 1989). That is to say, that they eventually die after suffering from one or more opportunistic infections.

## **PATHOPHYSIOLOGY OF VERTICAL TRANSMISSION**

Now that the risk of infection from the transfusion of blood and blood products has been greatly reduced with the onset of the testing of the blood supply, it is likely that virtually all newly acquired pediatric HIV infections will occur via vertical transmission. The mechanism and timing by which HIV is transmitted from an infected mother to her newborn infant, is not presently understood, but a potential exists for every HIV-infected mother to pass the virus on to her fetus. The route of transmission from mother to fetus remains unknown. HIV has been detected in aborted fetuses between 12 and 20 weeks of gestation, as well as in neonates using a technique called polymerase chain reaction (PCR) (Modlin and Saah 1991). At the onset of the epidemic the belief was that 100% of HIV-infected pregnant women transmitted their infection in utero. Currently it is estimated at about 30% predicted transmission (Repke and Johnson 1991). Early on in the epidemic only very ill women or those presenting with an opportunistic infection were seen to give birth to a infant that was ill at birth. Now that studies have been done of seropositive women in earlier stages of disease at the time of delivery, asymptomatic and seronegative infants have been observed. It is now apparent that the majority (70%) of infants of HIV-Infected women escape infection in utero. How those remaining infants (30%) acquire the virus from their mother has yet to be determined. Theories that are being explored range from infection occurring early in gestation, during the time of delivery as a result of contact with maternal blood or genital tract secretions (although cesarean section has not always prevented transmission), and the health status of the mother at time of pregnancy, particularly her stage of HIV disease which is thought to be a co-factor for transmission. The other mode of transmission from mother to infant is the transfer of the virus via infected breast milk (Modlin and Saah 1991). Diagnosing an infant for HIV is much complex, due to the fact that the infant passively acquires maternal antibodies that usually persist for about 15 months. Therefore most infants delivered of a positive mother, if tested, will be positive, but detecting HIV antibodies in an infant does not necessarily indicate the presence of the virus. Not until the infant sheds maternal antibodies can a positive test be an true indicator of infection. Usually a diagnosis of HIV infection in younger HIV-seropositive infants must depend on accompanying signs or symptoms suggestive of HIV infection or the identification of an AIDS-defining illness. There has been some progress in facilitating an accurate diagnosis in infants, but none has been widely accepted due to extreme expense, unreliability, and unavailability outside of selected research facilities. However, this is changing rapidly and new technology in the near future may solve this diagnostic problem. Implicit in the diagnosing of HIV infection in the child, is the revelation of the mother's serostatus. This raises serious ethical and legal questions involving the mother's right to informed consent, confidentiality and autonomy. The legal and ethical issues involved here are expertly discussed in Chapters 5-12 (Faden 1991) .

## **COUNSELING HIV-INFECTED WOMEN**

## **SCREENING TESTS**

To acquire a clinical diagnosis of HIV infection a screening test to detect the antibodies to HIV (ELISA) is performed. If positive, a second test must be performed called the Western Blot. In order to be considered positive for HIV, both tests must be positive.

## **PRE AND POST TEST COUNSELING**

In New York State it has been legally mandated that anyone who is tested for antibodies to HIV must sign an informed consent after receiving counseling which includes the clinical evaluation of the client's ability to absorb the information being given. This involves: gathering background data about the clients mental health, experience with handling crises and usual coping methods, the current stressors in the clients life, assessing how the client perceives personal risk of HIV infection; considering the availability of social and professional supports; evaluating how the client would react to the test result, whether it be negative or positive, and the clients understanding what both results mean, the possible consequences of being positive as it would impact on future health, the clients ability to infect both past and present sexual partners, and the need to become educated in preventative sexual practices that will reduce/eliminate the infecting of others in the future. If the client is a woman, understanding the potential for transmitting the virus to her fetus, if she is or becomes pregnant in the future. After this evaluation is done, the client then must be counseled regarding the possibility of discrimination with regard to housing, employment and insurance if the clients status becomes known to others (Van Devanter 1987). (10) One must remember that this test is not an indicator of anemia where the prescription and ingestion of iron would resolve the problem. Being diagnosed with HIV infection is generally accepted as having a life-threatening illness without the prospect of a cure.

## **BRIEF OVERVIEW OF THE MANAGEMENT OF THE HIV-INFECTED WOMAN, AND HIV-INFECTED PREGNANT WOMAN**

Currently the standard of care is zidovudine (AZT) in adults who are HIV-infected with a CD4 cell count of 500 or less. AZT has been found to delay the onset of symptoms in those that are asymptomatic, and to reduce symptoms in those who already have them. Bactrim, Dapsone or Pentamidine for PNEUMOCYSTIS CARINII pneumonia (PCP) prophylaxis for persons whose CD4 cell count is 200 or less. Prophylaxis for PCP has been demonstrated to reduce the risk of this life-threatening illness. It is important to note that most of the statistics gathered thus far have primarily been from male-dominated cohorts, and have not included pregnant women. Delay of development or progression of HIV-related illnesses during pregnancy is of obvious benefit to the mother and may be of benefit to the fetus. Presently there are studies underway following HIV-infected men who are taking AZT and how that drug might interfere with the efficiency of transmission in semen (Anderson 1991). Also, there is speculation that the use of AZT during pregnancy might reduce the risk of vertical transmission or at least delay the onset of symptoms in the HIV-infected newborn (O'Brien 1991).

Ethical issues regarding the use of AZT during pregnancy must be addressed. Do we risk the possible teratogenic, mutagenic, or carcinogenic effects to the fetus in order to provide treatment for the pregnant HIV-infected woman, or do we deny her right to treatment? At the same time, it is not possible to establish the efficacy of AZT in managing symptomatology in the pregnant woman and in the prevention of vertical transmission without exposing the fetus. Is it ethical to introduce a possible carcinogenic into the fetal environment, when present statistics suggest that 70% of those infants receiving the drug will not be infected? Alternatively, is it ethical to deny treatment to pregnant woman unless they agree to terminate their pregnancies? Presently, the only indication for the administration of AZT to a very ill pregnant woman is likened to the administration of chemotherapy to a pregnant woman with cancer (Repke and Johnson 1991).

## **OVERVIEW OF THE MANAGEMENT OF HIV INFECTION IN INFANTS AND CHILDREN**

Management of the HIV-infected child is basically that of the adult with a few exceptions. It has been observed that the incubation period (time of infection to manifestation of symptoms) is shorter in children who have acquired HIV perinatally than in adults. The average age of onset of symptoms in infants infected before or during birth is nine months. Of these children, 50% are diagnosed within the first year of life and 82% within the first three years (Caschetts 1991). A great majority of those infants who are born manifesting symptoms die within the first year of life. Encephalopathy is one of the most devastating conditions of HIV-infection in children, occurring in 50-90% of children with AIDS.

"Slow development in perception, intelligence and learning ability, and loss of acquired skills, including thought function, characterize this disorder of the nervous system." (Caschetts 1991).

## **ANTIRETROVIRAL THERAPY**

Administration of AZT has been approved by the FDA for HIV-infected children and the side effects are similar to that seen in adults; principally anemia and leukopenia (suppressed production of white blood cells). AZT has been found to be beneficial in children with advanced disease. Only the future results of research currently in progress will provide us the pharmacokinetics and safety of AZT in newborn infants and in third-trimester pregnant woman.

## **PCP PROPHYLAXIS**

PNEUMOCYSTIS CARINII pneumonia (PCP) is seen in approximately 39% of the opportunistic infections (OI) in children resulting in serious illness and death. It is recommended that children who are known to be HIV-infected, or infants born to a known HIV-infected mother and too young to obtain an definitive diagnosis, be started

on prophylaxis, specifically Bactrim (trimethoprim sulfamethoxazole). If they show an allergic response to this medication, dapsone or pentamidine may be substituted.

## **BACTERIAL INFECTIONS**

In 1987, the CDC modified the pediatric AIDS case definition to include recurrent serious bacterial infections as an AIDS-defining illness (MMWR 1987). These are treated with monthly administration of intravenous immunoglobulin (IVIG) prophylactically which provides significant periods free from serious illness and reduces hospitalization for HIV-infected children with more than 200 T4 cells (Caschetti 1992).

## **IMMUNIZATION**

Special attention must be given to routine immunizations to prevent illnesses, along with the consideration that infected children may have a poor or absent immune response to certain vaccines, and there may be potential risk of adverse reactions from live vaccines in an HIV-infected child. Asymptomatic children have more of an immune function, and have been shown to tolerate live vaccines (oral polio, measles, etc.) Also good nutrition, an important factor involved when treating any child, is imperative in the management of the HIV-infected child (Caschetti 1992).

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## **NOTES [CHAP 2]**

1 Most people do not know the irony behind this progression. Citizens of the United States are notoriously poor blood donors. Historically, homosexual men were heavily counted on by blood centers to be an important source of the blood supply they needed every year. This fact, has been turned against them since the onset of AIDS. Hemophiliacs, who counted on these blood donations to provide them with the life-saving clotting factor that they were lacking, soon became the recipients of these altruistically donated, but infected blood and blood products. Not until the onset of the antibody test in 1985, were any of blood donations screened for the HIV antibodies. For a background history of the onset of testing, please see:

Van Devanter, N. et al. (1987). Counseling HIV-Antibody 87, Positive Blood Donors, **American Journal of Nursing** 1026-1030.

Cleary, P., Van Devanter, N., et al. (1991). Behavior Changes after Notification of HIV Infection. **American Journal of Public Health** 81, 1586-1590.

2 There is much controversy over this redefinition of AIDS. Primarily the need for it came about after years of protest by activist groups lobbying for the inclusion of women into drug trials. For the majority of the first ten years of the epidemic, women were excluded if they were of "child-bearing age." This was, in part, due to the fact that men were almost exclusively seen as being infected by this virus. The biggest impetus behind

this, however, was the devastating results of the drug thalidomide given to pregnant women with the resulting deformities seen in the infants born of these women (primarily void of at least one limb). In addition to this, women infected with HIV were exhibiting some symptoms that were exclusive to women, primarily cervical lesions and vaginal candidiasis that was resistant to treatment. Aside from gender-specific symptomatology, this redefinition allowed both men and women, suffering from debilitating fatigue and wasting, who did not have an opportunistic infection as defined by the CDC, to become eligible for public assistance, specifically social security disability and much needed medical coverage that was lost through the inability to continue employment.

3 It is beyond the scope of this paper to go into the projection of this epidemic in the adolescent population, along with all the special difficulties that must be addressed when working with this population. At the very least, it is known that the majority of adolescents are not among those who are known to ponder their mortality, be able to delay gratification, reflect on causality, have good judgement or listen to, albeit delivered respectfully, counsel. All of which are factors that are imperative to the preventative component of this disease.

For more information see:

**Focus on Aids in N.Y. State**, Vol 3, No.2, (September 1991).

4 Another misconception surrounding this population of IVDU is that "once a junkie, always a junkie." Approximately 10% of addicts have managed to become productive members of society. They are not usually seen in medicaid funded infectious disease (ID) clinics, sexually transmitted disease (STD) clinics, detoxification (detox) units on an in-patient basis, or in methadone maintenance treatment programs (MMTP) where most studies are funded and statistics gathered. It is assumed at this time that arresting the disease of addiction can alter the progression of HIV disease in those who acquired their infection through the use of drugs. It is known that alcohol and drugs depress the immune system. As far as the preventative piece is concerned, there is no chance of changing behavior, specifically education in safer-sex practices, if a person is still active in his/her addiction.

5 The recognized routes of transmission are through sexual intercourse with an infected person, receiving HIV-infected blood either through a transfusion or contaminated needle-sharing equipment, perinatally acquired (vertical transmission) or infant acquired by nursing from an HIV-infected mother.

6 In addition to the misconception that to be at risk for AIDS, one must belong to a particular risk group, one of the most important conceptual flaws committed by most of the general population, and surprisingly many health professionals that would deny the progression of this epidemic across all "groups", is the latency period of this virus. It takes approximately 8-15 years from time of infection to the manifestation of the illness. This large gap of time renounces present statistics. Much like a research project whose data at time of publication is years old, the actual present demographics of this disease

are sorely under reported. This allows for the further spread of this disease, along with the horrific consequences of being unprepared as a society, a health care system, a community, and a family.

7 There is tremendous resistance on the part of the majority of citizens of the United States to accept that there is such a thing as heterosexually transmitted HIV infection. This epidemic is a spread of a virus that does not respect any socioeconomic, gender, ethnic, political or religious boundaries. However, the general population is aided in this resistance by the public health and medical professionals that would place the recognized heterosexual epidemic in Africa, for instance, as a Pattern II country distribution, which implicitly concludes that it would not be able to occur in the majority of the population as found in the United States except, of course, in the aforementioned homosexual, IVDU and the Afro-American/Latino communities.

8 For purposes of clarification, the index patient was that member of the couple who was defined as the potentially infectious person. When it was found to be that both members of the couple were infected, the index patient was then defined as the patient with a well defined risk for HIV infection. The contact was defined as the person of the opposite sex who reported multiple sexual intercourse with the index patient. If contacts reported other risks of HIV infection and/or other heterosexual partners with major risks for HIV infection, they were excluded.

9 Because some of these conditions are so common in women without HIV infections, they may be overlooked as potential indicators of HIV-infection. Also, one of the biggest barriers to diagnosis and treatment of women is the stereotyping that many health care providers continue to engage in, missing many of the white women that are infected, who are 26% of the total.

10 Unfortunately, this type of counseling is not always done. Personally, I have had clients who have reported being notified of their status by telephone when at work, implicitly by the refusal of life insurance, by their doctor at social gatherings, and other horror stories. If one can imagine oneself at the other end of this counseling, even at its best, you can get a taste of the fear and resistance that might be felt by the client.

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## **CHAPTER THREE**

In this chapter, I will discuss the role of both partners as it relates to reproductive responsibility and HIV risk reduction. I will look at the recommendations for HIV-infected women to abort, as well as the directive to forgo future childbearing. The quality of life of the child born of HIV-infected mothers will be addressed. The moral issues that are inherent in these situations will be explored. Then, I will examine the reproductive responsibilities of HIV-infected women in the short term. Finally, the long term responsibilities of society as it relates to this epidemic will be addressed.

### **INEQUITIES OF RESPONSIBLE HIV-PREVENTION AND PARENTING**

The major responsibility for reproductive decisions and raising children continues to fall on women, despite the changing picture of women in America today. This has historically been the case primarily because ours is a patriarchal society, and also because women alone possess the physiological ability to bear children. Even though it is not possible to change the biological model, to have the bulk of responsibility placed on one parent, for any reason, is an injustice to the child, as well as to women..

Society and the law underscores these inequities as is shown in the current heated debates surrounding proposed policies to allow men to take paternity leave, and for family members to be given a leave of absence in the case of a catastrophic event occurring within the family.

In the case of divorce, custody of the child/children is usually given primarily to the mother unless she is proven to be unfit. It is not assumed that both parents will be awarded joint custody. Difficult and passionate negotiating, frequently takes place if the father is to be awarded joint custody. This may have a further negative impact on the children, who are already trying to cope with the recent loss of their intact family.

It is not the purpose of this paper to go into a detailed description of the inequities of parenting but to point out that they do exist, and that it is Very much a part of the problem. Much of the literature about childrearing historically has centered around maternal responsibilities. This has insidiously impacted on the whole of society, but in the context of HIV, this problem has not been properly addressed. This is obvious in the rising statistics of HIV-infection in women acquired heterosexually, thus resulting in increasing perinatally transmitted HIV (Arras 1990).

To address only the woman is to address half the problem. For only a short period of time women have had at their disposal the means of being relatively free in choosing methods of birth control that did not involve the approval, nor cooperation of the male partner. However, in the context of HIV prevention, she must again look to her partner. The rising numbers of women being heterosexually HIV infected points to the lack of responsible



involvement of men in this epidemic. Our society also continues to reinforce inequities in the reproductive responsibilities of men and women.

The response of the media, which has such a large impact on forming normative behavior, has failed to react to this epidemic. It continues to promote irresponsible sexual behavior as being the essence of the male. In fact, it has been so slow to respond as to be negligent. The James Bond series long ago responded to the threat of AIDS by eliminating the free-flowing, unprotected, multiple encounters that were a trademark of Agent 007. I certainly am not advocating that we return to puritanical times. Quite the contrary, sexual activity with two responsible partners is a model of a norm that would be an asset to HIV prevention. The introduction of condoms into the busy bedrooms of the daytime television soap industry has raised more controversy than the sexually explicit material that is a norm in that format. There are many issues at work that impede the progress of HIV-prevention including, religious and secular objections to teaching safer sex in the schools and in the media. Others resist forces that would reduce irresponsible sexually explicit material because they view it as a threat to free speech. Can we respond to this epidemic with responsible representation of sexual activity, while maintaining free speech and individual beliefs?

This has been comprehensively stated (Bayer 1990a):

"The question that now presents itself is whether it will be possible, under contemporary political conditions, to frame an ideological perspective that will transcend those limits (liberal individualism) without calling forth the very conditions against which liberalism represented such a liberating challenge, that will be capable of informing the public culture within which women will make their decisions about reproduction."

## **OBLIGATIONS OF PARENTING**

The role of parenting has changed dramatically over time. Rutter (1952), discussed the role of mothering needed for a child's normal development:

"Mothering is a rather general term which includes a wide range of activities, Love, the development of enduring bonds, a stable but not necessarily unbroken relationship, and a 'stimulating' interaction are all necessary qualities, but there are many more. Children also need food, care and protection, discipline, models of behaviour, play and conversation."

He went on to conclude that the provision of these different activities, is imperative for the child's emotional growth, regardless of who the provider is. That provider does not necessarily have to be the mother, but the nurturing needs to be consistent in quality, not quantity.

Carol Levine (1990), in addressing the changing concepts of family in the context of AIDS, describes:

"Family members are individuals who by birth, adoption, marriage, or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need."

These two descriptions, although decades apart, and describing different types of family systems, seem to be saying very similar things. Certainly as it relates to this paper, the presence of a parent/family member is crucial to meet the obligation of nurturing which the child has a right to receive. Are we asking if the HIV-infected woman has the right to conceive or are we really asking if this woman is acting in a responsible manner? Is she able to foresee her possible death and plan for the continued nurturing of her child? Has she taken into consideration what stage of disease she might be in as it relates to perinatal transmission?

## **RECOMMENDATION THAT HIV-INFECTED PREGNANT WOMEN ABORT**

Most people are adamantly opposed to any HIV-infected woman conceiving or carrying to term. If we look back to Chapter Two, statistics relating to perinatal transmission of HIV are 30%. This very simply suggests that 30 out of 100 may be infected. We will have to wait for future studies to provide us with a more accurate picture. There is increasing evidence that a test which measures antibodies to the glycoprotein gp 120 may be able to predict the serostatus of the baby born to an HIV positive woman (Arras 1990).

## **THE NEED TO GUARD AGAINST AN ABUSE OF POWER**

However, given the absence of a accurate predictor of HIV infection in the fetus, recommending abortions could result in possibly 70 unnecessary termination of pregnancies. This recommendation is immoral, regardless of your stance on the abortion issue. Recommending abortions by abusing the influence that the physician holds over her/his patient is an immoral use of that power. To suggest the termination of 70 pregnancies merely to control for 30 pregnancies that could result in transmission of the HIV virus points to a level of emotional involvement that suggests hysteria, rather than concern for a public health issue.

## **INFLUENCE OF EUGENICS**

It also suggests an application of eugenics, the science that deals with the improvement of races and breeds, especially the human race, through the control of hereditary factors. Looking at the statistics of African-American and Latino population of women that are presenting with HIV infection, one does not need to be of color nor paranoid to see the implications that are implicit in this recommendation. There have been innumerable examples of racism, including forced sterilization of women, throughout our country's history. We must realize that much of it is so insidious that we have to be on guard to prevent further outrages. One need only to look back to the recent tragedy of the Tuskegee Syphilis Study 1932-1972, to be reminded of what can be done in the name of

science and medical progress (Thomas 1991). Will this same recommendation be in place when the majority of HIV infected women are white, someone we know, our sisters, ourselves?

## **RECOMMENDATION THAT HIV-INFECTED WOMEN FORGO FUTURE CHILDBEARING**

To address the further recommendation that HIV-infected women forgo future childbearing is not as clear cut, but equally fraught with emotion as well as public health concerns. Again, out of 100 potential children, 70 uninfected children would not be born. To be fair, most of the emotional reaction is based on those 30 babies that will be born infected and eventually die of this disease. What is the quality of life for these babies? Can the charge of "Wrongful Life" be brought against these mothers?

## **ARGUMENT OF WRONGFUL LIFE**

Wrongful life, as related to HIV, has been a most powerful argument, but is it an accurate one? For an HIV-infected woman to become pregnant would she place her baby at an unacceptable risk of catastrophic harm? Would this child have a life that no one would want to live? Wrongful life, a legal term (Feinberg, 1984) cited by Arras (1990), is such that:

"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."

The picture of the HIV-infected child as presented in Chapter Two, does not lead to this conclusion. Only a small percentage, approximately 10-20%, fit into the worst-case scenario, where a baby is sick at birth, and after a series of hospitalizations, will die before the age of two. The remainder will show a much more chronic picture, and live, perhaps, to the age of ten. These children will be able to live at home, go to school, and develop relationships with family and friends.

Referring to the description for basic human life as reflected by Kusche and Singer (1985), the HIV-infected baby more than meets that criteria at birth.

## **REPRODUCTIVE RESPONSIBILITY**

In looking at the reproductive responsibility of an HIV-infected woman to have a baby, I will explore the harm/probability ratio, the ability of the mother to care for her baby, along with the cost/benefit ratio to the mother, to the child and to society.

## **HARM/PROBABILITY RATIO**

Is it moral for an HIV-infected woman to consider having a child? If we had an accurate test to predict the serostatus of the fetus, we would at least be able to focus our efforts on defining the harm/probability ratio with much greater accuracy. That might enable most to concentrate both their emotional reactions, along with their public health concerns to an identifiable number of women. If such a test becomes available, it would allow for a greater choice by the woman, as is present for many genetic tests. Until this epidemic is more evenly distributed, it could reduce the socioeconomic, gender, and race issues that are implicit when discussing HIV and reproductive decisions. It would lessen the urgency of the physician who would be better informed as to the specifics of each and every case. At this particular point in time, however, we are restricted by the present statistics, and their limitations. If and when a more accurate test becomes available, the question of voluntary versus mandatory testing will most certainly come into play, as it has with voluntary versus mandatory testing of HIV-infected pregnant women. Possibly, it might dramatically reduce the perinatal transmission rates, as genetic testing for Tay-Sachs disease has been voluntarily endorsed by that community in which that disease prevails. HIV is a virus, not a genetic trait. If such a diagnostic prenatal test were available for HIV, the genetic model could be adapted for the purposes of reducing harm.

## **COST/BENEFIT CONSIDERATIONS**

Possibly, what many are objecting to is that the act of an HIV-infected woman becoming pregnant is "other regarding", that the potential harm is directed at another, in this case, her baby (Arras 1990). For many, to be able to rule out wrongful life is not sufficient. The claim of irresponsibility and wrongdoing on the part of the woman to expose her child to even a 30% risk of suffering and eventual death, remains. This now becomes difficult because different sets of values comes into solving the cost/benefit ratio that is involved here. Many would say, that 30% is too high to risk. Some HIV-infected women agree with this.

They find that it is unconscionable to consider becoming pregnant and placing their baby at such a risk. Others think differently.

The disadvantaged conditions that many HIV-infected women are forced to exist in can not be ignored. To do so would be too abstract a model to apply, appropriate only for a theoretical discussion. It would be correct to say that these women have a moral obligation to think of the risks that they are placing on their babies, as should any woman who is contemplating having a baby. Some would suggest that these risks are never considered by these women, for if they were considered, they couldn't possibly override them and decide to place these risks on their babies. Many have grappled with this problem: (Bayer 1990b)

"From the perspective of an infected woman whose own life prospects are not good and for whom the grim reality of an impoverished existence limits

options of every kind, the chance of having a healthy baby might seem worth the risks entailed."

Carol Levine and Nancy Neveloff Dubler have described the viewpoint of some poor inner-city women. Their lives, as described in chapter one, outlines the financial, physical and emotional poverty that these women find every day. For example, African-American women experience infant mortality rate of 19.2% v 9.7% for white women. This was expressed in number of deaths per year to infants under one year old per thousand live births, [\(b\)](#) With an infant mortality rate twice that of whites, a possible 30% risk of perinatal transmission may not pose as great a problem as it would to a woman who does not live in such a harsh reality.

Risk perception for anyone is a difficult process and is consistent with the world of that individual.

"Yet probabilistic reasoning--the weighing of risks and benefits, the ability to conceive of abstract harm, and the skill of distinguishing between likely and unlikely future consequences--is difficult for almost everyone."

"If older, "wiser" patients at risk for cardiovascular disease have trouble adopting risk- reduction behaviors, it is not surprising that young women find it difficult to embrace information arguing for behavior change that is difficult to implement and that removes an element of satisfaction from their lives." (Levine and Dubler 1990).

Some moralists would cry FOUL!. Is the philosophical sin of moral relativism being committed here? Is morality being compromised in this situation? Would the wrongs of society that have brought these women to the situations they now find themselves in be interesting, valid, but morally irrelevant? I will ignore the counter argument of universalizability that seems to be overlooked in this protest. That is the rule of consistency which states that if you think it is permissible for W1 to have a child, then you must consider it permissible for W2 to have a child if there is no relevant difference between W1 and W2. This is one way in which morality protects against bias and prejudice.

[b](#) National Center of Health Statistics 1986.

## **APPLICATION OF ETHICAL THEORIES**

If we address this issue on a purely theoretical model, what decision would we come to? Some moral philosophers argue that there are many types of practical dilemmas but never genuine moral dilemmas (Beauchamp and Childress 1989). Is it reasonable to adopt a nonnormative ethic, one that would not attempt to conclude with prescriptive guidelines, or would we have to look at this problem through an applied normative bioethical model?

I believe the latter approach considers the real dilemmas that exist. The issue of HIV-infected women bearing children, is frequently raised in the context of public policy.

"Public policy is composed of enforceable guidelines, governing a particular area of conduct, that have been accepted by an official public body--such as an agency of government or a legislature. The policies of corporations, hospitals, trade groups, and professional societies may have a deep impact on public policy, but their policies are private rather than public (Beauchamp and Childress 1989)."

I am reluctant to sanction any prescriptive guidelines which would violate a woman's right to reproduce, particularly in the presence of the overwhelming lack of justice that this population is exposed to. I would like to offer an example which is not related to HIV but shows a clear case of injustice analogous to those found surrounding this issue.

## **THE MYOPIC EYES OF BLAME**

Take the case of a pregnant woman, who while operating her car is seen to drive in a reckless manner, and becomes involved in an accident which results in her losing her baby. Is she said to be guilty in the death of her baby? Many would agree that she should have driven in a responsible manner that would not have endangered her baby's life and should be held responsible for the baby's death.

Another pregnant woman, under the same conditions, is seen to drive in a reckless manner, and becomes involved in an accident that endangers her baby's life. In this particular instance, however, the baby is not killed, but is injured which leads to a series of painful operations over the years before the child eventually dies as the result of those injuries.

It is later found that the majority of similar accidents, involving pregnant women who are seen driving in a reckless manner, result in neither the death nor any injury to the baby, but result in the death of the mother. In these instances the baby, if viable at the time of the collision, is delivered at the accident site.

So many of these repeated accidents occur that the public is made aware of them, resulting in an outraged cry to prevent any further tragedies from occurring. Upon initial investigation, these accidents seem to happen in clusters, restricted to a selected community. The community decides that any woman who becomes pregnant forgo driving, or forgo becoming pregnant if she wants to continue to drive.

Upon closer examination, it is found that the cars are defective and suddenly accelerate without the woman's cooperation or knowledge. It has been found that the manufacturer has been responsible for this defect, but has blamed the women in an effort to avoid taking legal, moral, and fiscal responsibility for this defect. In fact, the manufacturer claims that if the women never drove the car, the accidents would never have happened! The community, of which the majority are employees of the automobile manufacturer,

believe that this is the most expedient and least costly to the majority of the community. It has placed a referendum on the ballot to have pregnant women forgo driving these cars.

I believe the above case closely resembles that which is being demanded of a woman who is HIV-infected. This is clearly yet another case of blaming the victim. Many of the arguments oppose poor, disadvantaged women having children at all and this is further complicated when HIV is added.

Regretfully, the HIV virus can not be recalled. In presenting this case, I have attempted to crystallize exactly what I feel is being done to the HIV-infected woman. She is being blamed for the sum of the results of long standing neglect, discrimination and injustices that society has inflicted on her. It seems that our society will look at these injustices only when the result begins to impact on the public sector through the financial burdens of welfare, aid to dependent children, addiction related crimes, and now the HIV epidemic. Will this epidemic finally unblind those that think, "This is not my problem"?

If in the way we apply and reason with the conceptual category of individual moral rights, we destroy their capacity to ward off the always loud calls of aggregate social needs, will we not have jeopardized rights' moral power generally (Menzel, 1990)?

## **THE MANY PROFILES OF THE HIV-INFECTED WOMAN**

In both chapter one and three I have discussed many sets of circumstances that lead to the conception of a baby. I advocate that everyone consider, with much more thought, the importance of the role of parenting and its impact on the individual, the family (whatever form it takes), and the community. To plan responsibly and acquire the skills that are needed is an important foundation for good parenting. But to do so, all things should be equal. This is not the case with women in general, poor women in particular, and now HIV infected women.

I do not want to perpetuate a picture of woman as so victimized as to be helpless. Many women, despite the uphill battle, have been able to empower themselves to rise above these social crimes. All poor, disadvantaged women are not the same. Not all HIV-infected women come from poverty. Women, who are HIV-infected, are along many continuums that include socioeconomic, race, age, physical and emotional health status, and marital status. Some have had children, others have not. Along these varied continuum, there are women who have decided to voluntarily forgo their right to have children in light of their HIV-infection. Many do not have at their disposal, the means nor the desire, to consider the inherent issues. Some, as cited earlier, do not see being HIV-infected a deterrent to their already limited set of options in life. Still others, carefully weighing all the issues and options, decide to have a baby. Let us look at a few ethical theories and apply them to the problem of perinatal transmission.

## **THE INTERESTS OF THE WOMAN**

Deontology states that some features of acts other than, or in addition to, their consequences make them right or wrong and that the grounds of right or obligation are not wholly dependent on the production of good consequences.

...one must hold that at least some acts are right and others wrong, not because of their consequences but because of right-making characteristics such as fidelity to promises, truthfulness and justice (Beauchamp and Childress 1989).

In the light of the many injustices to women in general, and disadvantaged women in particular, the reproductive rights of women must be maintained, despite the danger of perinatal transmission.

Pregnancy should not be used to change the status of the individual in regard to her own body...We are in danger of creating of pregnant women a second class of citizen without the basic legal rights of bodily integrity and self-determination. (Rothman, 1989)

We must be aware of those issues of fetal rights and societal concerns that would interfere with women's rights to autonomy. It would be unjust to repeal the newly acquired, albeit unequal, rights that existing women are achieving to benefit the as yet unborn. One might use an analogous environmental issue to clarify this point:

Most of us would agree that we have to make sacrifices now in order to protect the environment in and of itself, and for future generations. We would probably agree to accomplish this by being prudent in our use of our resources. But would it be a just sacrifice to return to the pre-industrial society to protect the environment for future generations? That certainly would be reducing energy consumption. In fact, a return to manual labor, possibly acquired through slave labor, would accomplish these goals. As outrageous as that sounds, the rescinding of the prima facie right of women to reproduce, is equally unjust. We must be careful to define reproductive freedom to include the right to reproduce, as well as the right to choose, along with those options that would provide, the right not to reproduce.

## **THE INTERESTS OF THE CHILD**

When considering the interests of the child, most focus on the 30% that might be born infected, not the 70% that would be born healthy. I have addressed earlier in this chapter the charges of wrongful life and have discussed the risk/benefit considerations as related to HIV-infected children. Certainly, the interests of the child is a mute point if she is not born. I have previously gone over my thoughts regarding the prime importance in the role of parenting. I have communicated that I think too many of us do not give this right it's sacred duty. Therefore, let us look at all the children and their interests if born to HIV-infected women.

## **THIS MOTHER WILL DIE. WHO WILL CARE FOR HER CHILD?**



A common argument presented is that the HIV-infected woman should not have a baby because she will not be around to care for it, whether this baby is well or infected. Presently statistics strongly suggest a 100% mortality rate in those who develop AIDS, along with a belief that 100% of those infected with HIV will develop AIDS. Therefore, this argument is one worthy of discussion.

However, it does not take into consideration the exquisitely sensitive attention that an HIV-infected mother might bring forth to the nurturing of her baby. How many of us would approach such an important task differently if we knew we were going to die? In my work I have witnessed clients respond to the challenges of HIV, transcending many of the disadvantages and burdens that brought them to their present situations.

I would again point to the inequities in parenting that are implicit in this argument, is the mother the sole responsibility for childrearing? Where is the father, the invisible other parent? Are we assuming that in all cases of HIV there is no father? Or, are we assuming that in all cases of HIV, the father is also infected? If so, what value judgments are we bringing to this process? Should we begin again at the beginning, starting with the distinguishing fact that HIV is a virus? It is not a race, nor class of people, nor a lifestyle. Does this argument also ignore the family (whatever form it takes) as a source of nurturing, support, and structure for that child?

## **THE HIV-INFECTED MOTHER MUST PLAN FOR THE FUTURE CARE OF HER CHILD**

The belief that she will die, along with the health of the father, if present, are realities that must be explored by the HIV-infected woman if she is to make a responsible, comprehensive decision. What are her reasons for having a child at this time? What are her expectations of how her life will be like with this baby? What does she hope to be able to give to this baby? Is she being truthful to herself about the seriousness of her disease? Does she feel she will be a responsible mother? Is she being realistic in her ability to care for her baby? Does her partner, if present, realize the responsibilities he will incur? Does he feel he would have support from family and friends? Does she feel her family would be capable of and would commit to raising her child after her death or be a source of support to her partner in raising their child?

These are serious considerations to be brought into her formulation, as well as the resolution of these problems. Has she considered that her baby might be born infected? How would she feel if this was the case? Has she considered her baby being born sick and dying as she looks helplessly on? Has she ever spoken to another woman in this situation? Has she seen any babies that have been found to be infected (Arras 1990)? Does she feel that she and her partner, if present, along with whatever support network that may be in place, feel they can all contribute to the care of this baby? These are sobering thoughts indeed that tend to block out the thought of a cute, cuddly baby. This needs to be done if she is to make a decision anchored in reality. I do not believe, however, the reality of these problems should automatically eliminate reproductive considerations of HIV-infected women.

## THE INTERESTS OF SOCIETY

Consequentialism is the moral theory that actions are right or wrong according to their consequences rather than any intrinsic features they may have, such as truthfulness or fidelity. The most prominent consequentialist theory is utilitarianism. This theory

"refers to the moral theory that there is one and only one basic principle in ethics, the principle of utility, which asserts that we ought always to produce the greatest possible balance of value over disvalue (or the least possible balance of disvalue, if only undesirable results can be achieved"  
(Beauchamp and Childress 1989).

Regretfully, measuring disvalue seems the only possible way in the context of perinatal transmission. To take away the prima facie right of HIV-infected women to have children to protect the 30% of babies that might be born infected is unacceptable by this theory.

How is it different for society to contend with HIV-infected babies then babies who are born into poverty? Using utility one could argue both financially and eugenically, that an HIV-infected baby, with a shorter life expectancy, would cost less to society than the many long range burdens that evolve from poverty, discrimination and injustice. Is the interests of society so one dimensional? Where is justice being served?

## THE COSTS TO SOCIETY

As many as 10.5 million Americans are diagnosed with this disease.  
An average of 300 people died each day in 1987.  
This problem cost the nation an estimated \$85.8 BILLION in 1988.  
39% of this cost is due to reduced productivity.  
33% of this cost is due to mortality losses.  
25% of hospitalized patients suffer from this disease.

These statistics do not address the cost of HIV-infection, but do address the cost of alcoholism to society (NCADD 1990).

These costs far exceed the cost to society as compared with HIV. If that is the case, why then do we hear far more concern about the fiscal considerations surrounding the HIV epidemic than we hear about alcoholism? Is it because the consumption of alcohol is legal and within the boundary of normative behavior? Is it that this epidemic was initially seen to infect the disenfranchised? Is it because the results of substance abuse, whether legal or illegal, is a long range problem? The birth of HIV infected babies, admittedly, is a much more immediate problem. Can we as a society be as guilty in not responding to the substance abuse epidemic as those women who are accused of not being able to act in response to their HIV-infection?

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## CONCLUSION

I conclude that the recommendations for all HIV-infected pregnant women to abort, and for all HIV-infected women to forgo future childbearing are outdated, oversimplified solutions to this often emotionally charged, and realistically frightening epidemic. I continue to find that a majority of the public sector in this country, along with an alarming number of physicians, nurses, social workers, and members of the clergy are ignorant of many, if not all, the facts and issues that have been presented here.. In fact, it is this ignorance coupled with a cold indifference that many have toward anyone that is HIV-infected that lends credibility to my conclusion. How can anyone make a decision as emphatically as they do without knowing the facts?

I have attempted to look at the issues that are involved when HIV-infected women consider having a baby and when they decide to have a baby. I have looked at some of the arguments that are frequently brought against her and have tried to introduce those that would advocate for her. Clearly there are HIV-infected women who should not have a child due to one or more reasons, that may or may not have to do with having the virus, just as there are uninfected women who should not have a child. This epidemic brings with it medical, social and public health issues. It also comes at a time when it is being suggested that the rights of the fetus outweigh those of the pregnant women. However, it is imperative that the prima facie right of women to have a baby, as well as not have a baby, be protected regardless of HIV status.

The writing of this paper has not been an easy task. I bring to it as anyone would, my own personal and professional history. Also to it comes my neophyte grasp of philosophy and that of ethics, tempered with my experience as one who has been humbled by my working with these very women whom this paper addresses.

As has been noted throughout this paper, substance abuse has been linked to HIV-infection in women, whether directly or through sexual transmission from a partner. Most vertically transmitted pediatric HIV infections are also related to IVDU. Long before we will make any inroads into behavioral change that will impact on this HIV epidemic, we must better understand addiction as a genetically inherited physiological disease. We must look upon it as a public health issue, not a moral one. The implementation of voluntary HIV testing, free distribution of condoms and sterile needles, increasing treatment programs available for the arresting of the disease of drug addiction, recognizing signs and symptoms of addiction, educational programs addressing prevention of drug use, alerting those who may be genetically predisposed to addiction, are but a few of the ways that we can utilize prevention, the most efficient tool that we presently have against HIV-infection. For the past decade this epidemic of addiction has also been a vehicle for disseminating the HIV virus. How much longer will it take for us as a nation to respond to both of these epidemics? When are we going to see how the cycle of poverty, discrimination and addiction has assisted in the dissemination of the HIV epidemic? It is imperative that we see both poverty and addiction as co-factors for HIV-infection.

Are we also ignoring the public health issues of children, only to discover them as adults when they pose a risk of giving birth to children that might have a terminal disease? Just as prevention is the foundation of public health, it must also be the foundation of arresting the spread of this epidemic. Will we as an individual, a family, and a society be able to respond?

Personally, I tend to view HIV as a sexually transmitted cancer, and that we may not find a cure. In so doing, I am able to reframe what HIV means to me. I need to do this in order to insulate myself from all distractions and distortions that are inherent as a result of being a member of society, a health professional, a woman today, during the time of HIV.

Those scarred by suffering, those who have beheld--" You can, if you choose, enter into their consciousness and learn--without having gone through their hard school--to see and hear like one who "hath not" and from whom "shall be taken away even that which he hath". (Hammarskjold 1964).

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